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DOCTOR ON CALL
MAUREEN HANLEY, O.D.

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WALDENSTROM AND THE EYE

Dr. Maureen Hanley is a living legend to readers of IWMF-TALK. Whenever a question concerns the possible impact of WM on a patient's eye health there is certain to be a response from Dr. Hanley reflecting her training and experience as an eye care professional. A search of the TALK archives in preparation of this article produced no less than 152 such detailed answers to the concerns of other TALK participants. And whenever mention is made of an elevated level of serum viscosity there is sure to quickly follow the familiar, almost telegraphic,warning: "Be sure to get a dilated eye examination." In this article Dr. Hanley draws on considerable knowledge and experience to discuss specific ocular problems that a WM patient may encounter.

Many ocular problems can happen due to Waldenstrom's macroglobulinemia (WM). It is, however, important to remember that many things that happen to the eye are part of normal aging.

Focusing difficulties

In our forties or early fifties, for example, we begin to lose the ability to focus. This is called presbyopia. With WM, presbyopia may become more pronounced because one tends to become more fatigued. We may need bifocals to allow us to see at both distance and near.

Conjunctiva and Conjunctival Hemorrhages

The conjunctiva is a clear mucous membrane with fine blood vessels which lines the inside of eyelids and also covers the sclera (the white part of the eye). The conjunctiva can be affected by WM, and in this case the blood within the vessels of the cojunctiva may appear segmented and sluggish. The change in the conjunctiva can only be seen under an instrument called a slit lamp. Such changes also happen with almost all types of anemia.

Subconjunctival hemorrhages also occur commonly, whether or not the patients have WM. The hemorrhage occurs when a small blood vessel bleeds into the area of the eye between the sclera and the conjunctiva. When this happens, the sclera or whites of our eye look bright red. While a subconjuntival hemorrhage is usually harmless, if your eye looks abnormally red then you should certainly have it checked by your eye doctor. However, if you are taking Coumadin your INR (international normalized ratio – a clotting index) should be immediately checked and so, too, your CBC (complete blood count) values if they have been running low, especially your platelets. Also, you should notify your doctor if you have a bright red eye after plasmapheresis since your PT (prothrombin time – a test for clotting ability) and PTT (partial thromboplastin time) may be dangerously off.

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Dry Eyes

Dry eyes are a very common problem. Approximately twenty percent of all Americans suffer from dry eye symptoms. Dry eyes are even more prevalent in post-menopausal women, and WM may make this problem worse because it may have an autoimmune effect on the lacrimal gland.

In 2010 there are many treatments that can reduce the symptoms of dry eye and provide relief, such as punctal plugs (silicon or collagen pieces) inserted in the tear ducts to reduce the flow of tears to the nose and to keep them on the eye and the drug Restasis (ophthalmic cyclosporine) used to increase tears. Low-dose steroid drops may also be of help, in addition to the standard variety of artificial tears. It has been reported that WM can be associated with incapacitating dry eyes because of the infiltration of the lacrimal gland associated with secondary Sjogren's syndrome (an autoimmune disease that causes dry mouth and eyes). While this is a serious condition, Sjogren's syndrome is fortunately uncommon among WM patients.

Because of dry eyes, WM patients should be very cautious if planning for refractive surgery. Many surgeons will not perform refractive surgery on patients with autoimmune diseases.

In some patients with WM a diffuse or focal immunoprotein deposit can occur on the posterior part of the stroma of the cornea, but again this is rare and does not affect vision.

Cataracts

A cataract is an opacity of the lens. The lens is part of the focusing mechanism of the eye. The Framingham study showed that the prevalence of cataracts occurring without vision loss was 41.7% in persons 55-64 years of age and 91.1% in those of ages 75-84. The prevalence of cataracts with vision loss was 4.5% in persons 55-64 years of age and 45.9% in persons of ages 75-84. Essentially, if we live long enough we all will develop a cataract.

Many WM patients take steroids as part of their treatment. Steroids increase the chance of getting a certain type of cataract called a posterior subcapsular cataract. This type of cataract occurs at the back of the lens. A study found that 75% of the patients receiving more than 15 mg/day of prednisone for more than one year have this type of cataract.

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3932D Swift Road • Sarasota, FL 34231-6541
Telephone 941-927-4963 • Fax 941-927-4467
E-mail: info@iwmf.com • Website: www.iwmf.com

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

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

However, some studies suggest that the most important factor in steroid-induced posterior subcapsular cataract formation may be individual susceptibility. Other studies suggest the cumulative amount of glucocorticosteroid taken is the determining factor. The use of ocular or inhaled steroids has also been linked to cataract formation but does not pose as great a risk for cataract formation.

Glaucoma

Systemic and ocular steroids can also raise the intraocular pressure in the eyes. A patient is designated a steroid responder if their eye pressure increases while taking either a systemic or ocular steroid. A steroid responder may have to take glaucoma medications when a steroid is prescribed. Steroids appear to alter the outflow mechanisms in the trabeculum meshwork, a porous tissue that drains aqueous humor from the eye.

Most people think of glaucoma as high intraocular eye pressure (IOP) causing damage to the optic nerve. The most common type of glaucoma is called primary open angle glaucoma, and about two percent of adults over forty have this form. It is even more prevalent in African Americans.

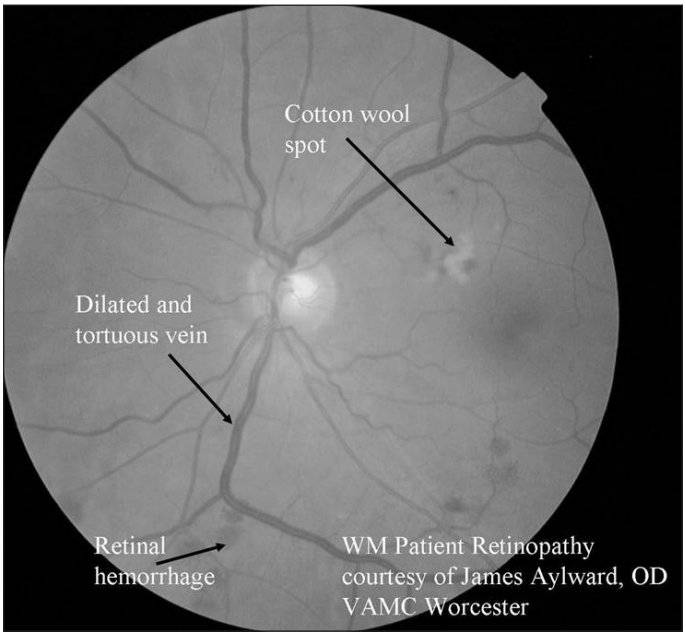
However, another type of glaucoma is called low tension or normal tension glaucoma. In this type of glaucoma the IOP is normal but the optic nerve develops the same type of neuropathy that is associated with high IOP glaucoma. Low tension glaucoma is thought to be a vascular problem of blood insufficiency or an autoimmune problem rather than a glaucoma resulting from increased IOP. Patients who are more prone to low tension glaucoma include patients who have systemic hypotension, anemia, cardiovascular problems, and sleep apnea. High serum viscosity (SV) also appears to be a risk factor.

High SV is thus a risk factor for both low tension and high pressure glaucoma. Research has also shown that about 30% of patients with low tension glaucoma have an autoimmune component. In general, low tension glaucoma patients have a much higher prevalence of monoclonal gammopathy compared with age-based normal individuals. The relation between monoclonal gammopathies and low tension glaucoma is a subject of current research. As of today, no research has been published on the reverse hypothesis: that is, if you have monoclonal gammopathy or WM, what is the risk of you developing low tension glaucoma? Whether or not low tension glaucoma is due to autoimmune neuropathy is also currently under investigation.

The Retina

When eye doctors hear the term Waldenstrom they generally think of the retina. Before discussing the retinal impacts of WM, it is important to know that hemorrhaging in the eye can also occur if one's hematocrit (HCT) is 50% below normal, especially if it is combined with thrombocytopenia (low platelets). Hypertension and diabetes can also cause retinal hemorrhaging in the eye, as can carotid artery blockage

Left eye of a WM patient with retinopathy



problems. Many other vascular diseases are associated with retinal hemorrhages.

When your eye doctor looks at the back of your eye (also known as the fundus) he or she can see the retina, the arteries and veins of the eye, and the optic nerve. In WM the earliest sign of a problem is usually venous dilation. Venous dilation and increased venous tortuosity can be difficult to recognize in their earliest state because many patients have congenital tortuous vessels. Congenital tortuosity is not associated with retinal hemorrhaging.

In the early stages of WM-related retinopathy, one can see small hemorrhages in the peripheral retina. Scleral depression is usually needed to see these peripheral hemorrhages. Scleral depression involves putting gentle pressure on the eyelids with a small metal probe (a depressor) to gently push the far peripheral retina into focus. This procedure adds about 2-3 minutes to a regular dilated exam.

As the WM-related retinopathy becomes more evident, hemorrhages increase in number, appearing in the posterior pole where the optic nerve and macula are located. Exudates (leakage of lipids) and cotton wool spots (microinfarctions of the nerve fiber layer that resemble cotton wool) can occur in addition to hemorrhages. The venous system becomes engorged via compression at arteriovenous crossings in the eye near the optic nerve. This can lead to branch-vein occlusions. Further engorgement or swelling of the veins can lead to optic nerve congestion and a central retinal vein occlusion. Not all individuals progress from one hemorrhage to a full-blown central vein occlusion. On the other hand, some individuals can have a clean retinal evaluation and later have a central vein occlusion in just weeks or months

Doctor on Call, cont. on page 4

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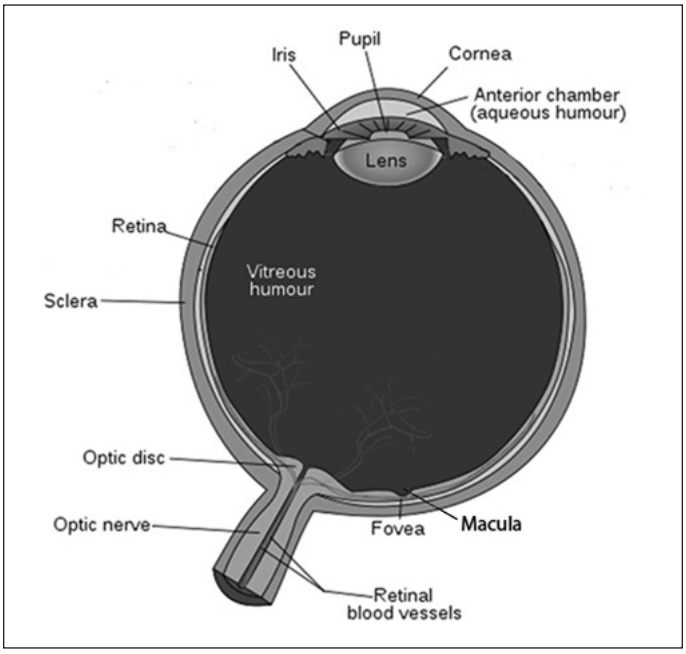
Schematic drawing of the human eye.
This is a diagram from the Wikimedia Commons.



following the exam. It is very important to realize that while not everyone with WM will have the retinal problems, it is estimated that about 40% will, and these cases appear to be related to SV, which in turn depends on the concentration of monoclonal IgM.

A study by Menke evaluated 46 patients with WM along with 14 age-matched adults without WM. The mean IgM level of patients with the first indications of retinal change was 4,732 mg/dL and a mean SV of 3.0 cp (centipoise).

Patients were divided into 3 groups:

Group 1: no retinopathy.

Group 2: dilated veins and /or peripheral hemorrhages; a mean serum IgM of 5,442 mg/dL (range of 2,950 to 8,440 mg/dL) and a mean SV of 3.1 cp.

Group 3: peripheral and central retinal hemorrhages accompanied by dilated veins, optic nerve head edema, and venous sausaging; a mean serum IgM of 8,515 mg/dL (range of 5,700 to 12,400 mg/dL) and a mean SV of 5.6 cp.

This study concluded that retinal changes were found in patients with SV values as low as 2.1; however, these changes produced no symptoms for the patient since the hemorrhages were in the far periphery. Clinically, the hemorrhages represent structural damage secondary to hyperviscosity. The hyperviscosity-related changes in the eye become symptomatic when the posterior pole becomes involved; the average SV associated with that effect was 5.6 cp.

Another study by the same group showed that plasmapheresis helped reduce the hyperviscosity-related retinopathy.

The Macula

The other important retinal finding noted with WM is serous macular detachment. The macula, the most sensitive part of the retina, provides fine visual acuity. Plasmapheresis and lowering of the IgM appear to be the only effective treatment for resolving serous detachments secondary to WM. Optical coherence tomography (OCT) does an excellent job of mapping these lesions. The cause of these lesions is unknown but appears related to increasing monoclonal IgM concentration that causes the transfer (by osmolar pressure) of normal fluids from the retina and choroid. Reducing the level of IgM systemically often results in decreased pressure within the subretinal space, with normalization of subretinal fluid dynamics and flattening of the retina. If, however, the macula sits in this fluid too long, the visual function will not return even if the retina flattens.

Cysts

Pars plana cysts may also develop in Waldenstrom's patients at the far periphery of the eye. Although shown by histopathological studies to contain IgM, these cysts do not affect vision. They may, in fact, be an aid in the diagnosis of WM or multiple myeloma (MM) since cysts of this type can develop in patients of both diseases.

Guidelines to Vision Health

As patients, we all want guidelines on how to protect our eyes from problems associated with WM. However, due to the rarity of WM, long-term clinical studies comprising large patient bases are unavailable and a firm set of guidelines for treatment protocol has yet to be established. By contrast, diabetic retinopathy has very specific guidelines concerning when to treat and when not to treat. The guidelines for diabetes were accomplished by studying over 3,000 patients for many years. In diabetic retinopathy the eye doctor does not use a laser to treat one or two hemorrhages but uses this technique exclusively to treat and diminish new blood vessel growth called proliferative retinopathy.

Years ago patients with eye pressures over 21 mm were regularly given eye drops to "treat glaucoma." Today only about 1 in 10 of patients with a pressure between 22-30 mm actually develops glaucoma. This was concluded from another large clinical trial called the Ocular Hypertension Treatment Study.

If a patient has posterior pole WM retinopathy or hyperviscosity maculopathy, most oncologists would treat the patient on the basis of these symptoms. The question becomes, "Should a patient be treated if their IgM is 4,000 mg/dL and there are only one or two retinal hemorrhages observed at the far periphery by scleral depression and the patient has no other signs or symptoms?" It appears that doctors have no consistent answer to this question of whether to treat or not under the circumstances described. What if a patient has an IgM concentration of 10,000 and both eyes look fine?

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Why does this patient not have retinopathy? Are they sitting on a "time bomb" and will this patient awake one morning with markedly reduced vision from a vein occlusion? Or, is there something unique to this individual that allows his or her venous system to tolerate the high IgM without an occlusion or hemorrhage? If I were the doctor of anyone with an IgM of 10,000 I would recommend some form of treatment to reduce the risk of eye damage from hyperviscosity effects and from all the other physical effects described in this article that could seriously and permanently cause vision loss.

So what can you do in 2011 to protect your vision if you have WM?

1. Get an annual or semi-annual complete dilated eye exam with a doctor who is comfortable examining a WM patient. Most doctors who see many diabetics should have no problem examining a WM patient since possible hemorrhages or tortuosity will appear very similar to what is seen with diabetics. It may take the doctor a few minutes to review a reference to vision problems associated with WM prior to the eye exam. The doctor may not be familiar with new findings related to employing scleral depression for peripheral hemorrhaging in addition to checking for macular serous detachments. The occurrence of so many possible eye diseases, coupled with the rarity of WM, explains why eye doctors, just like hematologists, may have little direct experience with WM.
2. Call ahead and ask before you make your appointment to be sure the doctor is comfortable seeing a patient with WM. If he or she is not, ask for a recommendation. If your oncologist is knowledgeable about WM they may be able to refer an eye doctor who is more experienced, especially if the oncologist has been referring other WM patients to the same eye doctor.
3. If possible, obtain retinal photographs. They are valuable, though not essential, to monitor changes in venous tortuosity over time.
4. Remember that you may be prone to low tension glaucoma even if your IgM is not high. Your optic nerve should be carefully examined, and if there is any question a visual field should be done that tests the sensitivity of your central and peripheral field of vision.
5. Be sure your eye doctor sends a report of your exam to your oncologist and encourage both to continue to communicate about WM and potential vision problems.

A final word from the wise: if you have any sudden changes in vision do **not** e-mail IWMF-TALK or try to self-diagnose. Go to or call your eye care provider immediately!

The author gratefully acknowledges the assistance of Ronald Draftz and Robert Gels in preparing this article.

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Dr. Maureen Hanley is a faculty member at The New England College of Optometry, a position she holds since 1984. She teaches course material involving diabetes, glaucoma, vascular diseases, corneal disease, optic nerve abnormalities, and visual fields.

Immediately after earning her doctor of optometry from the The New England College of Optometry in 1981, Dr. Hanley completed a residency in hospital-based optometry at the West Roxbury V. A. Medical Center. Dr. Hanley has practiced at many clinical sites; most recently she was a clinical preceptor and attending optometrist in the V.A. Boston Healthcare System for 12 years. Dr. Hanley has also been a certified reader of digital retinal images for the Joslin Diabetes Center in Boston. Since 2010 Dr. Hanley is in charge of vision services at the Jean Yawkey Place, providing eye care to homeless men and women.

In addition to her responsibilities with the college, Dr. Hanley frequently gives continuing education lectures to optometrists in the areas of visual fields, glaucoma, and ocular disease. Dr. Hanley is a member of both the American Optometric Association and the Massachusetts Society of Optometrists.

PRESIDENT'S CORNER

BY JUDITH MAY

Judith May, President

International WM Researchers meet in Venice

In October the Sixth International Workshop on Waldenstrom's Macroglobulinemia was held in Venice with 90 researchers attending from 11 countries, including 15 young researchers who are just beginning their careers. The IWMF funds the travel of these young investigators in the hope that we are creating the next generation of WM researchers. The focus of the workshop is solely Waldenstrom's macroglobulinemia research findings. This is the one event that brings together the global researchers who study our disease and who have recent results to report. It is an opportunity for them to hear other WM research presenters, to ask questions, and to discuss results and what might come next. The research workshops are held every two years and Dr. Steven Treon is the major organizer of this event. A workshop report will be published in the coming months.

It was very exciting to see the growing number of committed researchers and physicians in attendance. I have attended all the workshops since the first one in 2000, which was sponsored by the IWMF and NCI in Bethesda, MD, and had 19 attendees compared to the 90 in Venice. In a single decade we have leaped many decades in medical scientific progress and now have dozens of treatment options that did not exist ten years ago. Newly diagnosed patients today have many more treatment options due to the existence of these workshops.

The IWMF Scientific Advisory Committee

A recent appointment to the IWMF SAC is Dr. Stephen Ansell of the Mayo Clinic in Rochester, MN. Dr. Ansell is a hematologist-oncologist who sees many WM patients and is the current recipient of an IWMF research grant. We are delighted to have him join our SAC.

LRF Ed Forum – WM Seminar

In September the Lymphoma Research Foundation held its annual Educational Forum in San Francisco and once again offered us a large meeting room for the Waldenstrom's session. Approximately 50 patients and caregivers attended to hear presentations by Dr. Christine Chen of the Princess Margaret Hospital in Toronto and Dr. Steven Treon of the Dana Farber Cancer Institute in Boston.

These two physicians provided an interesting tag team presentation over several hours in which they addressed WM basics as well as future directions with new research results regarding diagnosis, current treatments and new treatments. Following lunch, patients had the opportunity to ask their questions for a full hour. Some of the new exploratory drugs designed to inhibit cell growth, increase cell death, and prolong survival are now in clinical trials. There will be information published in the near future on these findings.

We are very appreciative of the LRF's generosity in continuing support for WM seminars in their regional or national meetings. We are also enormously appreciative of the physicians who gave up their weekend to educate us.

IWMF Educational Forum – June 24 - 26, 2011

Our next Educational Forum will be held in Minneapolis, Minnesota, at the Radisson Plaza Hotel. You will be hearing a lot more about plans for this Forum in the months ahead. I would like, however, to give you a preview of what to expect. Our new format is to start with special plenary sessions at 9:00 a.m. on Friday morning. This year we have the special opportunity of adding a tour of the Mayo Clinic facilities for those arriving on Thursday. The day-by-day schedule is as follows below.

Thursday, June 23: On Thursday afternoon the Mayo Clinic is opening its doors for the IWMF. We will be treated to a tour of the facilities and learn the history of the Clinic. The Mayo Clinic is limited in the number of people who can tour the facilities, so we will have only one bus for traveling to the Mayo Clinic. The bus will hold 47 individuals. Only the first 47 to register for the tour will be able to take the tour. The cost per person is $20; this includes the round-trip bus ride and a box lunch on the bus. The bus will depart from the Radisson Plaza Hotel for the Mayo Clinic at noon.

Friday, June 24: Special plenary sessions in the morning include the topics of plasmapheresis, bone marrow biopsies, and CAM. A box lunch will be available for attendees from 12:00 to 1:15. At 1:30 sessions on genetics and a report on the WM mouse being developed for research purposes. From 3:15 - 4:45 we will be running breakout sessions: caregivers, veterans, newly diagnosed, pain management/PN, and estate planning. Friday evening we will hold the customary President's Reception and Welcome Dinner.

Saturday, June 25: Our agenda begins with an hour and a half of simultaneous sessions for newly diagnosed and veteran patients. This is followed by a two-hour series of presentations by a multi-disciplinary team from the Mayo Clinic. The team will include hematologists, neurologists, pathologists, nephrologists and scientists. You will have the opportunity to ask questions. Our afternoon sessions will focus on vaccine potential, unusual complications of WM, as well as reports on research findings.

Sunday, June 26: We will have the popular Ask the Doctor session, and the Board of Trustee's report to the members.

Once our agenda is set and speakers are confirmed you will receive more detailed information. I look forward to seeing you in Minneapolis.

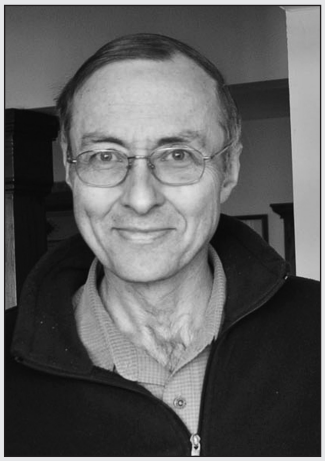
As we turn the corner and enter the year 2011, I wish you and your loved ones a very happy and healthy New Year.

Stay well,
Judith

DON LINDEMANN

December 17, 1951 - September 17, 2010

Don Lindemann



On September 17 the IWMF lost one of its strongest supporters and finest talents. From the first board meeting that Don Lindemann attended five years ago, it was obvious he was highly intelligent, sharp-witted, quick thinking, and totally committed to the IWMF cause of assisting and educating patients and finding a cure. His excellent writing and editing skills, sharp eye for detail, sense of humor, and natural negotiating skills resulted in Don becoming the editor of the *Torch*, chair of the Publications Committee, and member of the Ed Forum team, chairing several forums as well as proving to be our best negotiator with hotels. In fact, after Don planned his first Ed Forum, he wrote the definitive planning manual for our educational forums which we still use today.

We are all different in how we experience our disease, and Don had some extremely rare and even never-before-heard-of complications of WM. Don developed vision problems that eventually resulted in an irreversible and complete loss of vision, followed months later by a complete loss of hearing and extreme difficulty walking. At this point, Don decided to discontinue treatment and hospice was called.

Don had been a strong man who enjoyed many hiking and backpacking vacations. He developed special ties to a small indigenous village in Guatemala that he and his wife Ellen often visited and where they supported an elementary school. Don was an avid astronomer and several years ago established a Bay Area club for amateur astronomers. He was also one of the founding members of his Berkeley, California, cohousing community in which he created the lifestyle he was committed to living: a multigenerational intentional community of fourteen private homes and a shared common house built around a shared common green space. His interests and how he pursued them are emblematic of his determination, compassion, and love of life.

At the Celebration of Don's Life on September 26, and it truly was a celebration, friends and relatives recounted their memories of Don in a joyful way that was very special for this special man. His courage in addressing his loss of sight and hearing was amazing. He was a man for all seasons and will live on in our memories.

Judith May, President

SIXTH INTERNATIONAL WORKSHOP ON WALDENSTRÖM'S MACROGLOBULINEMIA

BY GUY SHERWOOD, M.D., IWMF TRUSTEE

The Sixth International Workshop on Waldenström's Macroglobulinemia (IWWM-6) was held October 6-10 in Venice, Italy. This premier scientific conference for WM was attended by close to 200 individuals from all over the world.

The 3-day workshop consisted of 17 lecture sessions and a total of 80 presentations from over 90 speakers, including 14 young investigators, 5 special guest presentations, 5 debates, and 2 consensus panel discussions. As is to be expected from such an intense 3-day workshop, the amount of new information can at times be overwhelming.

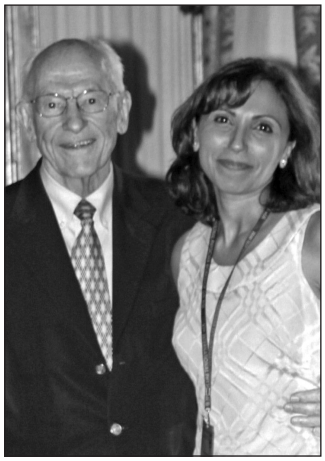
The international workshops also serve to recognize researchers who have made outstanding contributions in the field of WM research. During the opening ceremony of the conference at the beautiful Hotel Danielli, Dr. Irene Ghobrial was the recipient of the 2010 Robert Kyle Award. At this very same ceremony WM patient and conference benefactor Karen Lee Sobol spoke about her new book, *Twelve Weeks*, a memoir of her experience with a clinical trial that led to a complete and lasting remission

The workshop's closing ceremonies were held at the dazzling Palazzo Pisani Moretta. Dr. Eva Kimby, Dr. Jean-Paul Fermand, and Dr. Steven Treon were each recognized for their contributions to WM research and named recipients of the prestigious Waldenström Award.

Sixth International Workshop, cont. on page 8

The IWWM-6 workshop sessions were very well organized but extremely busy with rapid-fire exchange of the latest information on the pathogenesis, genetics, immunology, and molecular biology of WM, as well as the clinical features, treatments, and future directions in the treatment of WM. Over the course of the next few issues of the *Torch* I will attempt to briefly summarize the highlights from the workshop as well as give personal observations regarding presentations that struck me as particularly illuminating. A more complete summary of the Sixth International Workshop on Waldenström's Macroglobulinemia will be posted on the IWMF website in early 2011.

Dr. Robert Kyle congratulates the most recent Kyle honoree, Dr. Irene Ghobrial.



More information at http://www.wmsummit.org/wmwkshop/Venice-2010/Overview.htm and the complete abstracts at http://www.wmsummit.org/wmwkshop/Venice-2010/Abstracts.htm

Summary of the first session

The first session focused on the common challenges faced in the pathological diagnosis of WM. WM is defined as a lymphoplasmacytic lymphoma (LPL) with bone marrow involvement and an IgM monoclonal gammopathy of any concentration. The characteristic cells found in tissues infiltrated by WM cells are small lymphocytes, plasma cells and plasmacytoid lymphocytes, plus an increased amount of mast cells. Typically the ratio of B-cells to plasma cells in the bone marrow of a WM patient is 9:1. Establishing bone marrow involvement is fundamental in diagnosing WM.

Karen Lee Sobol spoke about the clinical trial that has brought her a complete and lasting remission.

There are several diseases similar to WM, including multiple myeloma (MM), IgM multiple myeloma (IgM MM), IgM monoclonal gammopathy of undetermined significance (IgM MGUS), and splenic marginal zone lymphoma (SMZL). The ability to further differentiate between these diseases and WM relies not only on clinical features but also on immunophenotypic differences, differences established by immunophenotyping, the technique used to identify cells based on the identification of proteins on their surface. When distinguishing WM from MM, the examination of the morphology (form and structure) of the plasma cell is the preferred technique. In WM, the more normal the plasma cells appear to be in the plasma cell component of the tumor mass, the better the prognosis. Distinguishing between IgM MM and WM is critical as management is significantly different for initial therapy (selection for autologous stem cell transplant and choice of long-term maintenance). IgM MM patients have a much shorter survival span than WM patients. The distinction between IgM MGUS and WM is based on two main features: the presence of bone marrow infiltration by lymphoplasmacytic lymphoma and signs or symptoms attributable to the disease. When making the difficult distinction between WM and its close relative splenic marginal zone lymphoma (SMZL), one notes that: SMZL has much more abdominal adenopathy and splenomegaly; 27% of SMZL patients are positive for the hepatitis C virus (versus 9% in WM); mast cells are relatively unimportant in SMZL; and, finally, WM presents with increased CD138 expression when compared to SMZL. It is therefore reasonable to suggest that the development of a specific WM immunophenotypic profile will improve diagnosis and permit more accurate identification of complete remissions.

The 2010 Waldenström awardees Dr. Eva Kimby, Dr. Jean-Paul Fermand, and Dr. Steve Treon.

Summary of the second session

The second session highlighted genetic predispositions to WM. Dr. Robert Kyle presented results from a long-term follow-up study of patients with IgM monoclonal gammopathy of undetermined significance (IgM-MGUS). Approximately 14% of the patients developed non-Hodgkin's lymphoma (NHL); of these, 3% developed WM. The probability of progression to NHL, WM included, was approximately 1.5% per year. Smoldering Waldenstrom's macroglobulinemia (SWM) is defined as a serum IgM $\geq$ 3 g/dL and/or $\geq$ 10% bone marrow infiltration but with no evidence of end-organ damage and symptoms that can be attributed to the disease. According to another study of Mayo Clinic patients with SWM, 71% had progressed to WM within a median of 4.6 years. The serum IgM level, hemoglobin value, and bone marrow infiltration were noted risk factors for progression.

A study of Italian patients with asymptomatic IgM MGUS revealed that approximately 10% progressed to WM after a

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median of 75 months. Of interest is the subset of IgM-related disorders (IgM-RDs) which are defined as IgM monoclonal gammopathies characterized by the specific properties of the IgM in question – cryoglobulinemia and activities characterized as anti-red blood cell, anti-platelet, or anti-nerve – without any evidence of lymphoma. IgM-RDs are thus similar to IgM MGUS because in both an underlying lymphoma is absent and both have a similar probability of transformation into a malignant disease such as WM. The probability of progression to a malignant lymphoproliferative disorder at 5 years was 15%. One can therefore state that although IgM-RDs frequently require treatment in view of their IgM related symptoms, the risk for malignant transformation is similar to IgM MGUS.

The familial (hereditary) predisposition in plasma cell disorders such as WM and MM is felt to be due in large part to genetic factors. Nonetheless, a chronic autoimmune response has been identified in MM as well as in WM. The existence of environmental risk factors for WM appears to imply chronic immune stimulation as well. In fact, studies examining familial MM and WM suggest common genetic and environmental factors in the etiology of both MM and WM. These factors, in turn, merit future intensive genetic and environmental investigation. In summary, increased familial risks of developing WM, NHL, CLL (chronic lymphocytic leukemia), and MGUS, as well as a personal history of certain autoimmune diseases (for example, Sjögren syndrome and autoimmune hemolytic anemia) and infectious conditions (pneumonia, septicemia, pyelonephritis, sinusitis, herpes zoster, and influenza) were strongly associated with increased risk of WM. Furthermore, familial WM patients were also more likely to report exposure to farming, pesticides, wood dust, and organic solvents compared to unaffected family members. Further evaluation of individuals who have a disproportionate number of family members with plasma cell disorders similar to WM has linked abnormalities in the biology of the B-cell to the development of disorders affecting IgG, IgA, and IgM. A prevalence of B-cell disorders is seen in up to 20% of patients with WM.

Finally, an increased incidence of second cancers has been reported in WM patients: 22 % of WM patients in a population study developed second cancers. WM patients were at increased risk for diffuse large B-cell lymphoma (DLBCL), myelodysplastic syndrome or acute myeloid leukemia (MDS/AML), brain cancer, and prostate cancer. The age, sex, or clinical and hematologic features of WM patients at presentation did not influence the risk of developing a second cancer.

Summary of the third session

The third session dealt with the very complex topic of genetic and epigenetic abnormalities in WM. Genetic abnormalities refer to changes in DNA sequences; epigenetic abnormalities refer to changes in appearance or gene expression caused by mechanisms other than changes in DNA sequences. Using very sophisticated and cutting-edge technology researchers are able to identify genetic aberrations, both those shared with other low-grade B-cell lymphomas and others that are distinct in WM. As an example, the genetic factors associated with the NF-kB pathway (a protein complex that controls the transcription of genes involved in cellular responses to stimuli such as stress and regulating the immune response to infection) were observed in around 70% of WM patients, but only in 20-30% of other common NHL disease types. Cytogenetic abnormalities in WM differ from those commonly reported in other B-cell cancers and confirm the originality of this disease (the 6q deletion is the most frequent reported cytogenetic abnormality in WM).

In addition to genetic abnormalities, epigenetic mechanisms that contribute to the inactivation of tumor suppressor genes by mutations have also been noted. It seems evident that there is progressive genetic instability in WM patients. WM tumor cells have variable rates of differentiation resulting in failure to fully undergo plasma cell differentiation. Analysis of genes involved in B-cell differentiation reveals the presence of factors that repress plasma cell differentiation while promoting tumor cell survival. Adding to the biological complexity of WM is the significance of the B-cell receptor in WM. The B-cell receptor (BCR) is a protein located on the outer surface of B-cells that binds with a specific antigen and causes the cell to proliferate and differentiate into a population of antibody (such as IgM) secreting cells. Recent studies from England have revealed that the WM tumor cells have an active and functional BCR, which can in turn be a potential therapeutic target with the newer targeted drug therapies.

Completing this very complex series of lectures was a special talk by Dr. Steve Bogen of Tufts University. We are now well aware that chronic antigenic stimulation (and genetics) contributes to the development of WM; what is of particular interest is the role of the monoclonal IgM in WM. Is this IgM production in response to an infection or just a simple error in genetics and cellular machinery? Research is now being conducted in the identification of the target of the WM IgM. Although for some the target of the IgM is the nerve coating leading to painful peripheral neuropathy, or perhaps the red blood cell leading to anemia, very early studies suggest that WM patients may actually share a common target (or targets) for the WM IgM such as an infectious agent. In fact, published experimental data have suggested that gammopathies (such as MM) may be associated with chronic exposure to an inflammatory and infectious stimulus such as the herpes virus.

Summary of the fourth session

The fourth session focused on immunological abnormalities in WM. One of the most interesting developments in immunology has been the study of T-cells in B-cell cancers. The regulatory T-cell (Treg, sometimes known as suppressor

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T-cell) is a specialized subpopulation of T-cells that acts to suppress activation of the immune system. Treg function was found to be frequently impaired in WM; this finding supports the contention that immune regulation defects may be responsible for the transition from MGUS to WM or MM. Furthermore, a newly identified CD4 cell population, the TH17 cells, important in the development of anti-tumor immunity and auto-immunity, were decreased in numbers in WM. The associated pro-inflammatory cytokines (molecular messengers) are elevated once again supporting the role of immune dysfunction in WM.

Other cellular elements of the immune system in WM patients such as peripheral monocytes (a type of white blood cell that can elicit an immune response) demonstrate a distinct genetic profile that is characterized by abnormalities in up genes affecting immunity, inflammation, and apoptosis (cell death). The antigenic targets of the IgM paraprotein in MGUS, MM and WM may play a role in these diseases. A recently identified protein of unknown function (paratarg-7) was identified as the antigenic target of a large proportion of familial WM patients. This protein and its associated gene that is dominantly inherited may indeed induce auto-immunity and contribute to the development of familial WM.

One of the more striking lectures of the entire workshop for me was the presentation by Dr. Andy Rawstron of Leeds, England, on the progressive humoral immune suppression in indolent B-cell malignancies. We know very well that recurrent infections are a major issue for WM patients. Simply put, it appears that in early B-cell malignancies, including WM, it is possible to detect normal B-cells in the majority of cases at presentation but subsequently there is a progressive depletion of normal B-cells over time. The depletion is independent of whether the B-cell disorder is stable or progressive – irrespective of IgM level. The depletion of immunoglobulins IgA and IgG (the condition called hypogammaglobulinemia) is also a relatively late event occurring approximately 2-3 years after normal peripheral B-cells are depleted. Measuring the depletion of normal peripheral B-cells may provide a better indicator for prognosis in patients with B-cell malignancies.

Summary of the fifth session

The final session relating to the basic biology of WM focused on the complex and sometimes bewildering topic of the molecular pathways involved in the growth and survival of WM. Appropriately Dr. Stephen Ansell from the Mayo Clinic led off the session with his lecture on the important cytokine IL-6 and its associated regulatory pathways. IL-6 significantly stimulates IgM production by WM cells. Inhibition of the regulatory pathway associated with IL-6 production may provide a valuable target in future therapies for WM.

The production of new blood vessels (angiogenesis) also represents an important step in the progression of WM. Serum levels of MIP-1α, a potent chemical attractant for macrophages and mast cells, which in turn contribute to increased angiogenesis, are elevated in WM. WM cells have been found to produce MIP-1α and may therefore present important implications for the treatment of WM.

Future therapeutic targets were also identified in this session. MicroRNAs are short non-coding forms of RNA that regulate gene expression and are in turn key regulators of WM progression. Studies have shown that the aberrant expression of regulatory miRNAs provides support for the development of targeted drug therapy in WM.

The session closed with a special lecture from Dr. Kenneth Anderson from the Dana-Farber Cancer Institute in Boston, MA. Dr. Anderson is a world-recognized expert in MM and has a keen interest in WM as well. His special guest lecture highlighted the recent advances in the biology of MM research and its potential applications to WM. Dr. Anderson discussed the peculiar and very important biology of the bone marrow microenvironment and the interaction of cancer cells (principally MM cells) and normal cells in this microenvironment. Elegant studies have demonstrated a key role for plasmacytoid dendritic cells (pDCs: specialized white blood cell that initiates a primary immune response by activating lymphocytes and secreting cytokines) in the growth, migration, and survival of MM cells. Dr. Anderson suggests that researchers may wish to evaluate the role of pDCs in WM.

This final lecture concluded the sessions on the basic biology of WM. The research in the basic biology of WM is expanding at an ever-increasing rate and represents the best hope for future targeted therapies in the treatment of WM. Although these topics are incredibly complex, and while many unknowns remain, researchers are making continued inroads into the understanding of this very challenging disease.

In the next issue of the *Torch* I will focus on the remaining sessions describing the recent advances in the clinical and therapeutic aspects of WM.

The 2012 Workshop (IWWM-7) is already in the planning phase and will be held in Newport, Rhode Island.

Donate and participate!

THE SECOND IWMF INTERNATIONAL PATIENT FORUM ON WALDENSTRÖM'S MACROGLOBULINEMIA

BY GUY SHERWOOD, M.D., IWMF TRUSTEE
AND CHAIR, INTERNATIONAL COMMITTEE

The second IWMF International Patient Forum on Waldenström's Macroglobulinemia was held in conjunction with the Sixth International Workshop on Waldenström's Macroglobulinemia (IWWM-6) scientific meeting at the beautiful and historic Molino Stucky Hilton hotel in Venice, Italy, on October 10, 2010.

This international patient educational forum was surprisingly well attended despite the expense associated with a visit to the beautiful and very touristy city of Venice. There was no registration fee associated with the patient forum, and breakfast and lunch were provided free of charge. We had well over 50 interested patients and caregivers from all over Europe attending the meeting. Among these attendees was a large representation of European support group leaders. Of note as well was the very welcome voluntary attendance of a large number of physicians who stayed beyond the IWWM-6 scientific conference in order to observe an IWMF patient education forum.

The patient forum started with an opening address from IWMF President Judith May, followed by a welcome from Dr. Enrica Morra (Italian WM expert and co-chairman of the IWWM-6 conference). Dr. Robert Kyle bravely led off the educational program with his lecture "Introduction to WM." Dr. Eva Kimby of Sweden followed with "Complications in WM," followed by Dr. Morra and "Current Treatments in WM." Dr. Charalampia Kyriakou (UK) spoke about the "Role of Autologous and Allogeneic Transplants in WM." Dr. Steven Treon finished the morning lectures with "Novel Treatments in WM." Dr. Kyle then reprised his very popular role as moderator for an extended "Ask the Doctor" session.

Lunch followed with many patients and caregivers expressing their enthusiasm for all the new information and the quality of the physicians' presentations. Following lunch Dr. Giampaolo Merlini presented a delightful talk on his close professional and personal relationship with Dr. Jan Waldenström. The IWMF International Committee chair then took the stage for a very brief presentation touching on the IWMF services available to WM'ers, the substantial amount of research being funded, as well as the role of the IWMF on the international stage. A patient panel followed where four patients (joined on stage by an unexpectedly gregarious patient from the crowd) related their experiences to the attendees. Breakout sessions then followed. The first session discussed typical issues of both the "newly diagnosed" and "veterans." The next breakout session consisted of three separate groups discussing mainly the challenges of international support groups: how to identify and recruit new patients and members, how to provide services such as printed information and website content in various languages, and, of course, the relationship between the IWMF and the new and fledgling support groups in Europe. The patient education forum concluded with a summary of the breakout discussions.

The IWMF Trustees and European patient support group leaders in attendance in Venice met over dinner later on in the evening to discuss issues pertaining to the relationship between the IWMF and European support groups, the possibility of future international WM patient forums, as well as support for regional patient forums including the UK WM patient seminar in London (January 2011) and the Waldenström's France patient meeting in Paris (September 2011).

The IWMF has as a part of its mission statement the education and support of WM patients – the second IWMF International Patient Forum on Waldenström's Macroglobulinemia is an example of the IWMF fulfilling its mandate to WM patients worldwide.

SCENES FROM THE IWMF INTERNATIONAL PATIENT FORUM IN VENICE

Venice photos courtesy of Roy Parker

A NOTE OF THANKS FROM THE IRISH SUPPORT GROUP

I would like to thank the IWMF and everyone associated with the International Patient Education Forum in Venice for the interesting and informative day which Sheila and I participated in. It was a wonderful day of meeting with other WMers from all over Europe and I believe some were from the US. It is such an important part of support group meetings to hear other people's stories, good and not so good.

I would like our thanks to be passed on also to the doctors who gave up their Sunday to help us after a grueling three days of their conference. It is very much appreciated.

The breakfast and lunch were delicious, as were the pastries etc. for coffee breaks.

The dinner in the restaurant on Sunday was really very special and our thanks go to Guy Sherwood for hosting it.

We are already looking forward to the next one.

Sincerely,
Anne Staples

HELLO FROM THE CHATEAU: A SURVIVOR'S STORY

BY DAVELL HAYS

In this personal reflection on her life since diagnosis with WM, Davell Hays recalls the early days of the IWMF in the era of founder Arnie Smokler when she was an officer on the first IWMF Board of Trustees. Davell describes how her spirited determination to reclaim her life led her first to several complementary and alternative approaches. Eventually, when the need for treatment was pressing, a double stem cell transplant gave her a new lease on life, a life that is active and fulfilling as she follows this personal credo:

Davell Hays

'I believe each of us should do everything in our power to remain healthy and not merely settle back waiting for doctors to produce the magic bullet. I don't feel that any one particular thing I did extended my life. I believe it is everything I did – both medical and non-medical. It is the very act of always striving to learn, to add new things to my self-treatment, and sometimes drop off old methods. It is my conscious decision to live.'

And live she does! Read on to learn more about this remarkable and vibrant member of the IWMF and her latest career in a family venture – a new "green" winery in El Dorado County, California.

I think most of us are pretty intuitive about our bodies and our health. Although I was not consciously aware that I was ill, my subconscious knew I had a serious illness. I was busy planning a wedding reception for my mother and could not pay attention to that inner voice. The night before the great event I went out to dinner with a cousin and after a few drinks told her I probably had a form of leukemia. I shocked myself. My symptoms were vague and doctors attributed them to stress, sinus infections, and such. I was 46. Finally, I went to a rheumatologist who diagnosed Waldenstrom's macroglobulinemia in 1993, about 7 years after symptoms started. The oncologist said I had maybe two years to live. When I asked if changing my diet would help, he said nothing would make a difference. Those first two weeks I started giving away my personal possessions and gave notice at work.

I took my shortened life sentence well. My best friend was shocked that I wasn't going to fight. But, when given no hope, most people accept the diagnosis. My friend, however, went online and found Arnie Smokler through the rare disease division for the Centers of Disease Control, where about 20 known cases of WM were on file. Arnie had started a chat line and shared information from his pharmaceutical background. I was reading a book about Co enzyme Q 10, which was not yet accepted in the US. I took the book to my next visit with my general practitioner and asked her opinion. She said she would not oppose its use and that I did not have to accept my verdict of death. I jumped up off her table and hugged her. I went out and changed my life. She gave me hope.

I then did everything in my power to take back charge of my health. I got a dog, took Tai Chi, went on a macrobiotic diet, and read everything I could get my hands on. I saw a nutritionist who practiced kinesiology testing (he determined what substances were good and bad for me by how my muscles

Hello from the Chateau, cont. on page 13

reacted when holding the substance). I took supplements to boost areas where blood testing showed I had deficiencies. Arnie and I began lengthy discussions both online and on the phone, I representing the alternative and complementary approaches and he the medical. I shared my information on the chat line that was growing daily. I became the group's spokesperson for non-medical approaches and often answered up to 40 e-mails a day. Where I had been fatigued, headachy, having a constant bloody nose and sinus infections, I now became healthy. None of my friends could keep up with me.

But my cancer continued to grow, and both Arnie and my doctors were quite concerned. Over the following years I was pushed to try medical treatments. But nothing I studied showed that this was anything but a short reprieve. Once started, I felt it would be a downhill spiral. And I felt wonderful. I fired that initial doctor and found one who treated me as a partner in my treatment. At that point, I knew about as much as he did about my disease. When I read new articles, new research, I would call the doctor who did the research and discuss his findings. I have no medical background at all, let me say. I worked for the Treasury Department. I was amazed when these wonderful, knowledgeable doctors would come right on the line. My first call was to Dr. Kyle, a man now so important in our disease. Another call was to Dr. Caggianno, who was involved with a clinical trial on hairy cell leukemia, using drugs now important in WM.

We decided to form the IWMF in order to fund research that the drug companies refused to undertake due to our small patient base. Our other aim was to share our growing information with newly diagnosed patients. We wanted them to know that there is hope. We formed the Board, and I became Secretary and a Trustee. We started raising funds, awarding research grants, producing publications, and growing, growing, growing. It was a 40- to 60-hour week, an essential part of our every waking moment. With my friend's assistance, I started a local support group. I organized the first few yearly IWMF educational forums, and, as a side benefit, discussed treatment methodology with the yearly presenters. I became a Lifeline counselor as well and talked to people around the world.

Finally, after 7 years, I could no longer delay treatment. The IgM level of 8000 was not yet causing irreversible damage, but my viscosity of 7 was an extreme danger. I would take plasmapheresis once a month to keep that level low, but after 30 days it would reach 7 again. A stroke seemed imminent. So I entered into a clinical trial supported by my doctor at the medical facilities of the University of California Davis in Sacramento. In 2000 I did two stem cell transplants within the year, with my own stem cells. I invited my doctor to make a presentation at our local support group meeting and three others did the tandem stem cell transplants as well. When harvesting my blood, they brought in doctors to look at it. They had never seen anything so rich. This was the ideal. Normally it could take a week of harvesting to get enough cells for two transplants. Yet in 6 hours they had enough cells for 3 transplants. My insurance denied payment for the procedure because it was experimental. But my doctor wanted me to live. He paid for the transplants out of his research funds – a $250,000 expenditure.

The purpose of two autologus transplants was to catch any remaining cells the first one may miss. First I gave myself daily shots to force the growth of stem cells which would then spill out of my marrow into my bloodstream. The blood was filtered to capture these cells for the harvest. Then I entered the hospital, armed with all the tools I acquired to make this successful. I had wristbands as a form of acupressure to avoid nausea, brought an egg crate mattress to be more comfortable, had hypnotherapy, made an affirmation audio tape with the help of a general practitioner specializing in complementary methods for fighting disease. Instead of get well cards, I requested pictures of the senders. I then had images of you all, people I knew from chatlines and phone calls but had not seen. I put your pictures inside red hearts that I used to adorn my hospital room. I was surrounded by your love and support. I had a prescription for marinol, a pill form of marijuana, by far the best thing for nausea, depression and the fried brain feeling the chemo would cause.

The first two days I received enough chemo to kill me within two weeks. The third day my stem cells were returned to me to quickly repopulate my body and to begin to overcome the damage from the chemo. The side effects, though, would linger for many months while I was in isolation.

The transplants were very rough. After the first one I said I would rather die than do another. But, like having a baby, you forget how terrible it was. So I did the second one. There was scar tissue in my chest due to a catheter I had for one year. When they placed a new catheter in my chest for the second go round, it hit the scar tissue, turned inward, and punctured my lung. This wasn't discovered for three weeks, at which time my survival was in doubt from fluid in the lungs and severe septicemia. The last thing I remember was screaming as a stake was pounded through my ribs to drain the fluid.

I quit the Board after the first transplant, while I was still organizing the Ed Forum from my hospital bed. I needed to turn my attentions to my husband, who was retired in 1998 due to dementia at the age of 53. He died last year and did not know me for the two final years.

The above history gives you facts but does not talk about attitude. Attitude is everything. It is the difference between life and death. Although my history sounds dismal, it was not. Not ever. Life is what you make it. Only the first two weeks after diagnosis was I sad. After that I have known the joy of living every day. I jet ski, motorcycle ride, play water volleyball on summer days, play pinochle and bunco, square dance, and travel. In order to help care for my husband those

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last three years, my son and his family and I bought 13 acres and entered into the wine business. That way we could all be together to care for my Vern.

We opened our tasting room for sales 6 months ago and our sales are 300% above expectation. We have no employees; we grow the grapes and all our food, harvest, blend, bottle and sell. We are organic and biodynamic. We increased our production this fall, also by 300%. It's a 7-day, 10-hours-a-day work week. But it is incredibly fun and rewarding. It is never too late to learn new things. And since May I have sold over 90 pieces of jewelry at the tasting room. I create these in the middle of the night. I am a 62-year-old grandma and I unloaded 2000 pounds of grapes by myself last Wednesday. Go figure!

For pictures of the winery and my family, go to any search engine and put "Chateau Davell" in, and then follow the Facebook site. Yes, my son named it after me. Life is good.

I miss my IWMF family and am so happy that Judith is President and that you have hung on to Sara. The whole team is incredible. My love to all of you and best wishes for health and happiness. Oh, my IgM has been about 2000 for the past 5 years. My body is controlling it on its own. Howard, your Lifeline contact, is one of the four who did the transplants at the same time I did. We are all doing well.

COOKS HAPPY HOUR

BY PENNI WISNER

Because of health issues, Nancy Lambert has told me that she can no longer contribute to our column. But she continues to inspire me. I've based this column around an e-mail exchange of several years ago. And when you take your healthy snack out to watch the sunset – this is the season of great sunsets here in Northern California when the piled clouds catch and reflect the pink light – please join me in raising a glass to Nancy and to her speedy recovery.

Back then, Nancy had just discovered – by way of New Zealand – an Egyptian spice mixture called dukkah. It's a blend of nuts and seeds, ground to a coarse paste, and usually served with bread dipped or brushed first with olive oil. It reminds me of another Middle Eastern herb blend that has become a favorite, za'tar, a mix of thyme, oregano, and sesame. Which reminds me of baharat, a blend of cinnamon, allspice, and clove (I just slow roasted a lamb shoulder rubbed with that). Which reminds me of ras el hanout which can have upwards of 30 ingredients (and tastes great with roasted winter squash). All of which says, to me at least, that such blends can enliven your winter cooking by adding complex, perhaps exotic, new flavors to your kitchen standards just the way a jazzy interpretation of a ballad gives you new pleasure in an old favorite.

Spice blends, even those with names and generations of history behind them, vary from kitchen to kitchen, season to season. If you don't have or don't like or are allergic to an ingredient, leave it out, or substitute another one. If there's an ingredient you like or have a lot of – in my case chile, mint, and oregano – add some. Over time, your recipe will differ from mine and that's the way it should be. I'll give you some parameters, and then, I hope, you will go about embroidering and making the mix your own.

To make dukkah, take two big handfuls of hazelnuts and roast them in a 375°F oven, shaking the pan occasionally so the nuts brown evenly, until fragrant and toasted, about 10 minutes. Wrap them in a kitchen towel and set aside for a few minutes. Then grab the towel and rub the nuts briskly against each other to remove the skins. Dump the nuts into a colander with fairly large holes and shake to separate nuts from skins. Put the nuts in a food processor or use a mortar and pestle. Add anywhere from a few tablespoons to a half cup (see what I mean about not worrying?) sesame seeds that you've toasted lightly in a dry skillet over medium heat. Add 1 to 2 tablespoons coriander seeds and about half as much cumin seeds (unless you love cumin, in which case add the same amount as you did coriander). You can toast these, too, as you did the sesame seeds, but it's up to you and your patience. Add a healthy dose of freshly ground black pepper (the finished mix should have a slight kick) and about a teaspoon of kosher salt or half as much sea salt. Now pulse the mix or pound with the pestle until you have a coarse blend. Scrape it into a jar and refrigerate it for up to several weeks.

Some dukkah recipes I've seen include roasted chick peas, or dried mint, and/or fennel seeds. As I said, variety is the spice of life. (Oh dear, that's bad isn't it?). Sprinkle dukkah on toasted bread drizzled with olive oil. Or on your baked or mashed potatoes (russet or sweet), over green beans, broccoli, roasted fish or chicken or turkey, hummus. Etc. Etc.

Since nut-spice mixes may not be your thing, and because Alice suggested leeks as a topic, and they are in season throughout the winter (and because dukkah would taste great with this preparation), I want to share with you an incredibly easy and delicious way to cook leeks. Perhaps I reveal too much when I say that I often plan to serve these with a

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vinaigrette as a first course but I usually just end up picking them up with my fingers and eating them while they are still warm. You could use a fork and knife.

Buy yourself a bunch of leeks not more than about an inch in diameter. Cut away the dark green tops, wash them, and save them for stock making. Trim away the roots, and then cut the leeks in half lengthwise without cutting through the root end so the whole leek stays together. Soak the leeks in cool water, then swish them through the water and make sure no dirt is caught between the leaves. Arrange the leeks flat in a heavy pan. Add a couple tablespoons of dry white wine or water and a couple tablespoons of extra-virgin olive oil, plus salt and pepper to taste. If you are not going to use dukkah or a vinaigrette, add an herb such as thyme, dried or fresh. Cover the pan and place over medium heat. Cook without peeking or disturbing the pan for about 10 minutes, then uncover and check for doneness. The leeks should be tender and most of the water boiled away. Don't move the leeks, but let them continue to cook, uncovered, over medium or medium-low heat, until they brown on one side. Then turn them over carefully with tongs and let the second side brown. Transfer the leeks to a warm serving dish and resist them if you can.

Our motto: Eat Well to Stay Well

WE GET E-MAILS!

I especially enjoy the Cooks' Happy Hour in the *Torch* – it is the first section I go to when I get it. I enjoyed doing the olive tapanades and bruschetta – very refreshing for a very hot summer!

Paula Austin

MEDICAL NEWS ROUNDUP

BY SUE HERMS

Occupational Exposure to Solvents and Lymphoid Cancers – A multi-center study in France reported by the Centre for Research in Epidemiology and Population Health investigated the role of occupational exposure to solvents in the occurrence of lymphoid cancers in men. The data were generated by six French hospitals during the period 2000-2004. Exposure to solvents was assessed using standardized occupational questionnaires and case-by-case assessment. Specific quantitation of benzene exposure was attempted. The analysis included 491 male patients (244 non-Hodgkin's lymphoma, 87 Hodgkin's lymphoma, 104 lymphoproliferative syndrome, and 56 multiple myeloma) and 456 male controls. The conclusion was that solvent exposure in general was marginally associated with non-Hodgkin's lymphoma but not with other lymphomas; there was also no trend with the average intensity or frequency of exposure. Exposure to pure benzene at high levels was associated with diffuse large cell lymphoma but not with other lymphomas.

CD20 Expression and Effectiveness of Rituximab Therapy – A study published in *Oncology Reports* attempted to determine the cut-off value of CD20 expression in B-cell lymphomas together with the predictive significance of better outcome with rituximab treatment. The introduction of rituximab into the treatment of B-cell lymphomas has improved the overall response rate, as well as the response duration and the overall survival of patients with B-cell lymphomas. However, only a few studies have addressed the question of whether higher CD20 expression parallels better treatment outcomes. In this study from 2003-2007, 114 patients with different types of B-cell lymphomas treated with rituximab and chemotherapy were assessed. All patients had CD20 expression measured prior to treatment with quantitative flow cytometry. The cut-off value of CD20 expression which predicts a better response to rituximab was determined at 25.000 molecules of equivalent soluble fluorochrome (MESF). The data showed that patients who achieved complete responses after rituximab therapy had a significantly higher expression of CD20 than those whose disease only stabilized after treatment. A higher level of CD20 expression also correlated with an improved overall survival. The authors suggested that this cut-off value be considered when the decision regarding treatment with rituximab is taken; however, further studies on larger groups of patients were also suggested.

European Study Reports on Long-Term Dosing Studies of Rituximab Therapy in Follicular Lymphoma – A multi-center European trial published in *Clinical Oncology* focused on long-term results of a randomized study of follicular lymphoma patients, comparing single-agent rituximab induction therapy once per week for 4 weeks vs. rituximab induction therapy followed by 4 cycles of maintenance therapy every 2 months. The 202 patients (64 chemotherapy naïve and 138 with prior chemotherapy) received rituximab and if responsive were randomly assigned to either observation or four additional doses of rituximab. At a median follow-up of 9.5 years, the median event-free survival was 13 months for the observation arm and 24 months for the prolonged rituximab exposure arm. Of the previously untreated patients receiving prolonged rituximab exposure, 45% were still without event. No long-term toxicity potentially due to rituximab was observed.

FDA and Orphan Drug Development – There is an initiative underway to revamp the way the U.S. Food & Drug

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Administration (FDA) approaches orphan drug development. The 2010 Brownback and Brown amendment to the 1983 Orphan Drug Act was created as a market-based approach to address rare and neglected diseases by incentivizing biotech and pharmaceutical companies to invest in drugs for these conditions. Designing drug trials for orphan diseases has historically been challenging: recruiting sufficient numbers of patients is difficult; many rare diseases manifest very differently across patients; and the etiology and natural course of rare diseases are poorly understood. The FDA has traditionally stated that orphan drugs are to be held to the same laws and agency guidelines as drugs for more common diseases. Public hearings have been underway to suggest ways in which the FDA might be more flexible when weighing approval of orphan drugs. There were also calls for development of comprehensive patient and disease databases, the use of scientifically accepted biomarkers as clinical trial endpoints, and suggested changes in patent protection for companies developing orphan drugs.

Specific Protein Inhibition Improves Stem Cell Therapy Efficiency – Researchers at the Institut de Recherches Cliniques de Montreal have found a protein than can regulate certain characteristics of blood stem cells, thereby increasing the efficiency of stem cell therapy. In mouse models, the protein called Gfi1b was turned off. This led to the stem cells becoming activated, expanding drastically, leaving their bone marrow niche, and entering the bloodstream without losing their function. The next goal of the researchers is to investigate the precise molecular mechanisms involved in Gfi1b inactivation.

Two Bortezomib Dosing Schedules Evaluated for Efficacy – St. Bartholomew's Hospital in London evaluated bortezomib (Velcade) and rituximab in Phase I and Phase II studies of patients with mantle cell lymphoma, follicular lymphoma, and WM. In this randomized study, 42 patients with recurrent or refractory disease received either bortezomib at 1.3 mg/m^2 twice weekly with rituximab vs. bortezomib at 1.6 mg/m^2 once weekly with rituximab. The main toxicities were neurological, gastrointestinal, and hematological. The overall response rate was 67% and by histology: mantle cell lymphoma 58%, follicular lymphoma 53%, and WM 90%. Toxicity and efficacy were equivalent between the two groups.

The Effect of Fludarabine/Cyclophosphamide on Subsequent T-Cell Response – Recent therapeutic advances in leukemia and lymphoma therapy have suggested that tumor-specific T-cell responses can be generated by immunization of patients with peptides derived from their tumors and infused, thereby activating the patients' own immune system. A study from the Paracelsus Medical University Salzburg tested whether the use of fludarabine and/or cyclophosphamide would interfere with this therapeutic strategy of T-cell activation in patients with chronic lymphocytic leukemia. Analysis of peripheral blood samples from patients prior to and during fludarabine/cyclophosphamide therapy revealed rapid and sustained reduction of tumor cells including CD4+ and CD8+ T-cells. Unexpectedly, T-cells surviving fludarabine or cyclophosphamide treatment had a more mature phenotype and were significantly more responsive to subsequent stimulation. The researchers concluded that fludarabine or cyclophosphamide therapy, though inducing significant and relevant T-cell depletion, seems to generate a milieu suitable for subsequent T-cell activation.

Oral Bcl-2 Inhibitor Enhances Chemotherapy Responses – Researchers at Global Pharmaceutical Research and Development reported that the oral Bcl-2 inhibitor ABT-263 enhanced the response of several chemotherapy regimens in cell line and animal models of B-cell lymphomas and multiple myeloma. ABT-263 was tested in combination with VAP, CHOP, and R-CHOP, as well as single agents including etoposide, rituximab, bortezomib, and cyclophosphamide and demonstrated superior tumor growth inhibition and delay, along with significant improvements in tumor response rates. The major toxicity appeared to be a reduction in circulating platelets in animal models.

Bisphosphonates May Increase Risk of Thigh Bone Fractures – The American Society of Bone and Mineral Research has warned that the popular osteoporosis drugs known as bisphosphonates may increase the risk of rare but painful thigh bone fractures. The group identified 310 such fractures from case studies and found that 94% of people who sustained these fractures have taken bisphosphonates for more than five years. The FDA has been waiting for this report before making recommendations on labeling of these drugs which include Aclasta, Actonel, Aredia, Bondronat, Boniva, Didronel, Fosamax, Fosavance, Reclast, Skelid, and Zometa.

European Group Reports on Allogeneic Stem Cell Transplants in WM – The Lymphoma Working Party of the European Group for Blood and Marrow Transplantation reported on long-term outcomes of allogeneic stem cell transplantation as a therapeutic option for WM patients. A total of 86 patients received allogeneic stem cell transplantation by either myeloablative (MAC) or reduced-intensity (RIC) conditioning regimens and were retrospectively studied. The median age at transplant was 49 years; 47 patients had received three or more previous therapies and eight had experienced failure on a prior autologous stem cell transplant. Median follow-up of surviving patients was 50 months. Nonrelapse mortality at 3 years was 33% for MAC and 25% for RIC. Fourteen patients received donor lymphocyte infusions for disease relapse. Progression free survival and overall survival at 5 years were 56% and 62% for MAC and 49% and 64% for RIC. The occurrence of chronic graft vs. host disease was associated with a higher nonrelapse mortality but a lower relapse rate. The study concluded that allogeneic stem cell transplant can induce durable remissions in a selected population of young and heavily pretreated WM patients.

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The lower relapse rate in patients developing chronic graft vs host disease suggests the existence of a clinically relevant graft vs. WM effect.

Two Enzymes May Impact Studies of PI3K Lymphoma Therapies – The Sanford-Burnham Medical Research Institute published a study exploring the roles of two enzymes, called SHIP and PTEN, in B-cell growth and proliferation. These enzymes act cooperatively to suppress B-cell lymphoma, a finding that could impact several anti-lymphoma therapies currently in development. Both SHIP and PTEN keep a damper on PI3K, an enzyme that promotes cellular growth, survival, and proliferation. P13K signaling is altered in a number of different cancers. This study supports the development of anti-lymphoma drugs that mimic PTEN and SHIP activity by inhibiting PI3K.

NICE in the United Kingdom Refuses to Recommend Several Cancer Drugs – The National Institute for Health and Clinical Excellence (NICE), which is the United Kingdom's cost-effectiveness regulator for drugs, has refused to recommend several cancer drugs, including Arzerra (ofatumumab) for chronic lymphocytic leukemia, Torisel (temsirolimus) for mantle cell lymphoma, and Levact (bendamustine) for indolent non-Hodgkin's lymphoma. NICE recommendations are required in order to use drugs through the U.K.'s publicly funded National Health Service. Arzerra was rejected due to its unfavorable cost vs. benefit ratio, while Torisel and Levact were rejected due to lack of evidence for efficacy from the manufacturers, Pfizer and Napp Pharmaceuticals, respectively.

Association of Fludarabine and Mitoxantrone with Myelodysplasia and Acute Myeloid Leukemia – The Department of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, Australia, investigated the incidence and characteristics of treatment-related myelodysplasia and acute myeloid leukemia after treatment with fludarabine combination therapy for lymphoproliferative disorders. In all, 176 patients treated with fludarabine combination therapy were followed for a median of 41 months. Nineteen cases of treatment-related myelodysplasia or acute myeloid leukemia were identified for an overall rate of 10.8%. Median overall survival after diagnosis was 11 months. Patients developing this complication included follicular lymphoma 20.4%, chronic lymphocytic leukemia 6.1%, and WM or marginal zone lymphoma 12.5%. Most patients had other cytotoxic treatments. Of the eleven patients who received mitoxantrone with fludarabine, 36.4% developed the complication. There was also a trend toward prior cytotoxic therapy increasing the risk.

Oral Drug CAL-101 Study Reports Phase I Results – CAL-101, an oral inhibitor of PI3K that induces apoptosis of NHL cell lines, was evaluated in a multi-center Phase I study for its safety and activity in patients with relapsed or refractory hematologic malignancies. The study enrolled 55 patients, 28 with indolent NHL (follicular, small lymphocytic, WM, and marginal zone) and 27 with aggressive NHL (mantle cell, diffuse large cell). Overall response rates were 65% for indolent NHL, 62% for mantle cell lymphoma, and 0% for diffuse large cell. The median duration of response had not been reached in indolent NHL patients. Symptomatic adverse events were neutropenia, lymphopenia, thrombocytopenia, and elevated enzymes ALT/AST. CAL-101 was developed by Calistoga Pharmaceuticals.

Genmab Announces Phase III Study of Ofatumumab vs. Rituximab in Follicular Lymphoma Patients – Genmab has announced the start of a Phase III study of single agent ofatumumab (Arzerra) compared to single agent rituximab in patients with follicular NHL that have relapsed at least 6 months after completion of treatment with a rituximab-containing regimen to which they responded. Approximately 516 patients will be randomized to receive ofatumumab or rituximab for four weekly doses. Patients who have stable or responsive disease will then receive single infusions of ofatumumab or rituximab every two months for four additional doses for a total of eight doses over nine months. The primary endpoint is progression free survival.

Dana-Farber Reports Impact of Rituximab Responses on Progression Free Survival in WM – Dana-Farber Cancer Institute examined the impact of categorical responses on progression free survival in 159 rituximab-naïve WM patients who received rituximab-based therapy. All patients received a rituximab-containing regimen with either cyclophosphamide, fludarabine, bortezomib, or an immunomodulatory agent. The median follow-up was 35.3 months and categorical responses were are follows: complete response 8.8%, very good partial response 13.2%, partial response 50%, minor response 18.9%, and non-responders 8.8%. Achievement of better responses was incrementally associated with improved progression free survival. Median time to progression for complete response and very good partial response was 71.8 months vs. 38.6 months for partial response and minor response. Additionally, the favorable genetic polymorphism of at least one valine at the FcyRIIA-158 position in the patients' effector cells also predicted for improved responses.

Canadian Researchers Develop Blood Cells from Skin Cells – Researchers at the Stem Cell and Cancer Research Institute at McMaster University in Canada have discovered growth factors that reprogram skin cells into blood cells. The researchers found that they needed to activate a single gene called OCT_4 in the skin cells and that the cells required precisely calibrated combinations of 4-6 growth factors to make a variety of blood cell types. The transformation was completed without first converting the skin cells into stem cells that are normally used for transplantation. By skipping the stem cell step, the researchers believe they have skirted the risk that replacement cells might form dangerous tumors.

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Medical News Roundup cont. from page 17

Since the source of the cells would come from a patient's own skin, there would also be no concern about rejection of the transplanted cells. The discovery was replicated several times over two years using human skin from both young and old people to prove that it works for all ages. Clinical trials could begin as soon as 2012.

Phase I and II Trial Evaluates Clofarabine – A clinical trial performed at Lutheran General Advanced Care Center in Illinois evaluated the efficacy and safety of clofarabine in relapsed/refractory non-Hodgkin's lymphoma. Clofarabine is a purine nucleoside analog. This combination Phase I and II study determined the maximum tolerated dose at 4 mg/m^2. Of 33 patients who were enrolled, 31 patients were evaluable for an overall response rate of 47% and median response duration of 7 months. Toxicity was mainly hematologic (neutropenia or thrombocytopenia).

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

REGULAR GIVING TO THE IWMF

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

The IWMF is now in its second decade of serving Waldenstrom's macroglobulinemia patients and their families. On October 1, 2010, we launched our new website (same address: www.iwmf.com) which is easier to use and provides updates on all of the information that so many new patients are eager to find after their initial diagnosis. We also enhanced the "Giving" and "Join & Help" sections to provide you with more information and more options for giving to our unique organization.

As before, you can use your credit card to donate online. If you prefer, you can print a giving form from the website and mail it with your check. We now offer you the new option to give either monthly, quarterly, or annually for a selected number of years. This is available for both the Member Services Fund and the Research Fund, which are kept in separate accounts. The more years you pledge to give, the better we can plan for member services operating costs and research expenses. We encourage you to consider pledging a gift for a period of 3-5 years to the fund of your choice – Research or Member Services – or you may divide your gift between the two funds.

The Member Services Fund is the lifeblood of our organization. Our overhead is low at 15%, which covers the

Regular Giving to the IWMF, cont. on page 19

Giving Circle Descriptions for the Member Services Fund

WMer ($1-$99 annually)
This is the first level to join the WM Family. The IWMF is grateful for all gifts.

Circle of Friends ($100-$299 annually)
Join the WM Circle of Friends and help support the distribution of information about WM to all patients.

Support Group Circle ($300-$499 annually)
A gift at this level honors and encourages the IWMF support groups.

WM Family Circle ($500-$999 annually)
Your gift at this level honors the extended family of patients, families, friends, physicians and researchers.

Caregiver Circle ($1000-$2499 annually)
This level of giving honors our caregivers, our doctors, and our nurses for their personal care and guidance.

President's Circle ($2500-$4999 annually)
The IWMF is where it is today due to the dedicated efforts of past Presidents Arnie Smokler and Ben Rude and of current President Judith May. Giving at this level acknowledges their hard work and commitment.

Trustee Circle ($5000 or greater annually)
Pay tribute to the volunteer Board of Trustees by giving at this level. Your gift makes a significant statement to the leadership that you are behind them in our mission to improve the quality of life of Waldenstrom patients and to find a cure for our persistent orphan disease.

Note: all levels from Support Group Circle and above offer a monthly giving option.

Regular Giving to the IWMF, cont. from page 18

salaries of our wonderful part-time support staff at our small office in Sarasota, the cost of printing and mailing the *Torch* and IWMF booklets, the annual Education Forum, and all other membership costs. The new monthly gift plan suggests a minimum starting amount of $25 per month, or $300 per year. This amount places you in the new "Support Group Circle," one of the seven new more personalized giving levels for our Member Services Fund only, defined in the Annual Giving Circles chart. Of course we are grateful for any amount you wish to donate.

Contributions to the Research Fund are exclusively for the support of WM research studies. Once money is designated for research it stays in the Research Fund where it is used for critical projects such as our three newest research studies: the cell line project, the mouse model, and the WM tissue bank. Your research contributions also enable us to fund exciting genetic and molecular studies that have potential for remarkable progress in understanding how WM develops and the differences in how it is expressed in various patients.

The Board of Trustees, our all-volunteer Board, is extremely thankful for your incredible generosity in the past. Many of the more common types of cancers receive national support and pharmaceutical funding; however, the IWMF relies upon our members' generous gifts for patient services and research. If you have any questions on your giving options, or do not have access to the website, please contact Don Brown at 630-323-5894 for Member Services gifts or Carl Harrington at 267-519-8175 for Research Fund gifts.

Thank you for your wonderful support and caring for our WM family and the IWMF. Let's start the New Year with a renewed commitment to improving our quality of life and the hope of finding a cure.

Have a happy and healthy New Year!

FROM IWMF-TALK

BY MITCH ORFUSS

Perhaps a result of our collective childhood school calendar, fall is a second start each year. With the soft, warm breezes of summer fading behind us, it's time to get back to work. In that spirit, TALK picked up its usual brisk pace a beat across a wide variety of topics stimulating considerable online information and support for the 1000-plus TALK readers who derive benefit from keeping up with, and weighing in on, what is top-of-mind for so many others who walk in our shoes and seek the community of fellow travelers. "Waldenbury Tales." What follows are some of the discussion topics generating lively TALK discussion since the summer of 2010:

Spleen issues

Splenomegaly is a not uncommon symptom of WM. **Rodger Coon** reported that together with an enlarged spleen he developed hemolitic anemia. His spleen had grown so large it was touching the tip of his bladder and partly covering and displacing the stomach. After Rodger had the spleen removed, the anemia stopped. Before the spleen was removed, he'd had several inoculations for pneumonia and later on a shot for spinal meningitis. **John3474** added that when he was diagnosed with WM his spleen was slightly enlarged and RBC, HCT, and HgB were slightly below normal range. John3474 received many different drugs to raise the platelet count. He eventually had his spleen removed. The platelet count then rebounded but for only a month before dropping to 10,000. It wasn't until six months later, when he had 6xR-CHP, that the platelet count returned to normal. After that treatment his RBC, HgB, and HCT rose to normal range within three months.

IgG and IgM

Larry Genge's recent numbers were IgG 300, which is low, and IgM 5600, which is high. Larry's hemoglobin was 11.3. He asked if he could possibly have multiple myeloma instead of WM. **Susuma Ata** is a caregiver to his wife with MM. He believes that 300 IgG is extremely low and that Larry may be substantially more susceptible to infections. Given that Larry possibly needs IVIG, Susuma suggests that Larry speak to his doctor. **Colin Rainford** replied that having low IgG is a common problem associated with WM and unfortunately also from several of the treatments. As for MM and IgG, it's Colin's understanding that a patient's IgG increases rather than falls as a side effect of MM. Ever

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HOW TO JOIN IWMF-TALK

Here are two ways to join:

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

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

since Colin's diagnosis he has also had low IgG in the 300 range, and he suggests that Larry take care to avoid infection with regular handwashing, good food preparation, avoiding people with colds, and so on. Generally Colin gets by okay with a low IgG but presently has a cough he can't shake off after catching a cold three months prior.

Role of Genetics

Joe Sergio wrote that though the exact cause of WM is not known, scientists believe that genetics may play a role in WM because the disease has been seen to run in families. This caused Joe great anxiety. He had heard of one family (mother and daughter) each having both cold agglutinin disease and WM, and asked if anyone reading TALK had heard of a similar case. **Paul Listen** responded that both he and his father had been diagnosed with both MGUS and WM. **Robert Reeber** replied that, as with many diseases, there is a genetic variety WM and the garden variety, which most of us on TALK have. Chazz from Cleveland added that at 65 he was recently diagnosed at Taussig Cancer Center, The Cleveland Clinic. His identical twin brother unfortunately had died of Hodgkin's lymphoma at 29, and Chazz's assumption is that there is cellular change that creates both diseases. **Ted Moore** added that his father, who had WM, died in 2000 at age 85 after 19 years with WM. Ted got his diagnosis in 2006 at 67, almost the same age as his dad when he was diagnosed. Curiously, Ted's son-in-law's father has WM, so his granddaughters have two grandfathers and a great grandfather with WM.

Fludarabine or R-CHOP

Gerda Diekmeyer sought opinions about fludarabine vs. R-CHOP. **Dr. Tom Hoffman** replied that R-CHOP has more potential short-term toxicity; Rituxan plus Fludara delivers more potential long-term toxicity whereas Rituxan plus bendamustine is perhaps the best but studies are still ongoing. Why not just R as a choice? It appears to have worked for Gerda for the last year. Perhaps, Tom added, you need maintenance Rituxan.

Miriam Hart responded to Gerda, suggesting that her numbers look pretty good and perhaps she requires no treatment whatsoever. Miriam said that from her father's experience, fludarabine was anything but 'an easy treatment' with 'minimal side effects'. Her father had received only the combo of FCR and so Miriam could not contrast it to solo fludarabine. Her father was well and had low IgM when he started FCR. The first two treatments "were a breeze" but the third one almost killed him. He experienced severe damage to his immune system, leading to shingles, pneumonia, and mouth and throat sores so painful that he stopped eating and ended up in hospital on a feeding tube. At the end of chemo he had lost 65 pounds. At the time of writing, Miriam's dad was evidently recovering from the pneumonia and slowly learning how to swallow and speak again. WM experts, she said, seem now to suggest combo treatments such as BDR as first-line treatment rather than FR or FCR or R-CHOP. Perhaps the best thing to do is to get a second expert opinion.

Anita Lawson said that after choosing fludarabine as first-line treatment following her 2003 WM diagnosis, she felt it was a pretty easy treatment, less than an hour for the infusion each day for five days in a row every four weeks. Minimal side effects (mild occasional nausea and fatigue) and – for Anita – excellent results. Many, however, warn about the threat of transformation down the road.

Elective Surgery during Treatment

Richard G asked if it is advisable or foolish to have arthroscopic shoulder surgery while taking fludarabine. **Sarah FitzGerald** replied that though she is not on fludarabine, she is still on maintenance Rituxan and had just had major shoulder surgery after a car accident. She was nervous about surgery, being a slow healer even without "the fun effects of chemo." Sarah did check with her hematologist-oncologist and with Dr. Treon beforehand, and they both took a good look at her blood work, serum viscosity, and general health before approving the surgery. **Patricia Roberts** added that she was not even allowed to get her teeth cleaned while on chemo with fludarabine and Rituxan. **Dr. Tom Hoffman** advised that Richard would never be able to make that choice because no surgeon would ever agree to operate.

Sue Brown finished a series of four fludarabine treatments in June, 2009, and in October had arthroscopic shoulder surgery. Her WBC was still low at the time (and still is). Her orthopedist consulted with the oncologist, who said okay to go ahead. Sue had no problems, and at the time of writing, her shoulder felt great. **Malcolm Walpole** said that he personally would not recommend surgery of any description while on fludarabine. It is well known that patients receiving this drug frequently develop neutropenia, thrombocytopenia, and anemia. Patients are prone to opportunistic infections which can be life threatening.

What about plasmapheresis (PP)?

Michael Luttrell spoke on what they don't tell you about PP:

1) PP can dramatically increase IgM production. Michael had 16 PP treatments with no other interfering treatments or issues and discovered that his rate of IgM production increased from pre-PP rate up 30 to 50-fold! How can this be? There is a very strong set point for IgM (and probably most blood factors) which the immune system is determined to hold. The set point can be normal or, in our case, aberrant, a homeostasis or inertial function. Drive it down, it bounces back. In spite of the shibboleth that we are all different, in truth, we are all more alike than different. Michael believes this is a universal phenomenon, like gravity or momentum. Most PPs are done pre-Rituxan, and appropriately so to prevent IgM flare. Michael has not found anybody who has carefully documented the results before and after every treatment. But he

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believes if multiple blood tests were done then his experience would be repeated by others.

2) PP removes all large proteins along with serum, which is then replaced with sterile albumin, devoid of the proteins removed, like IgA, IgG and other essential proteins. The other Ig's will plummet to near-zero, perhaps increasing the infection risk.
3) In order to keep IgM below any particular value (Michael was striving for less than 1,000) the frequency of PP had to be increased to as often as 2x/week.

Other TALK discussion revolved around such considerations as amyloidosis, high glucose, chronic cough, the role of genetics, kappa/lambda ratio, and CT scans. Remember that TALK exists for information and support, but not for the practice of medicine. Participants are encouraged to share their experiences dealing with this disease, and readers are encouraged to understand each TALK entry as an outpouring of good will and solidarity that is however the product of one individual patient's experience – that's all. Caveat emptor and good health to all!

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 25-26.

IWMF CHAPTERS – USA

CALIFORNIA

Sacramento and Bay Area

In September the Lymphoma Research Foundation (LRF) held an educational forum in San Francisco. Not just one, but two breakout sessions focused on Waldenstrom's. Dr. Steven Treon from the Dana-Farber Cancer Institute in Boston and Dr. Christine Chen of the Princess Margaret Hospital in Toronto gave presentations and then generously answered numerous questions during a special luncheon held specifically for the Sacramento and Bay Area support group. After the lunch, the group continued to meet for a caring-and-sharing session. Then at the end of January the group gathered again, this time in the newly built wing of Kaiser Hospital in Vallejo. **Penni Wisner**, a former group leader, spoke on "Turning Nutrition Advice into Easy, Healthy Recipes" and brought some examples – baked kale chips was one – for everyone to sample. Time was also given for members to talk about their latest happenings.

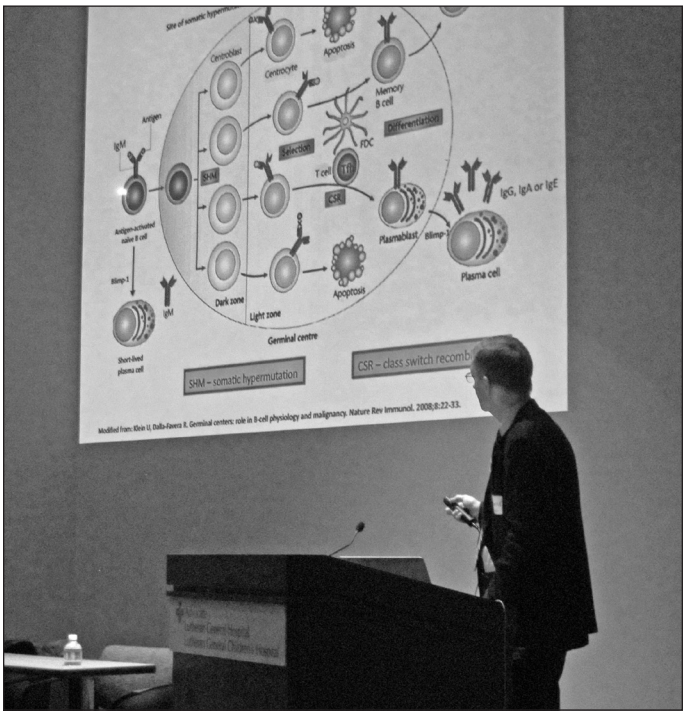
COLORADO & WYOMING

Twenty-six members of the Rocky Mountains support group met early in November at the University Park United Methodist Church in Denver. New members introduced themselves and older members brought the rest up to date. Then the group watched Dr. Julie Nielson's presentation given at the IWMF Las Vegas Ed Forum in April 2010. A lively discussion followed this 35-minute portion of the DVD. Members agreed that, thanks to grants from the IWMF and some individuals, much far-reaching research is being done on WM and advances in knowledge about WM seem to be happening faster than ever before. **Roy Parker** gave a presentation on the highlights of the Sixth International Workshop on WM in Venice, sponsored by the Bing Center at the Dana-Farber Cancer Institute. He and his wife Eileen attended this October conference. Roy showed pictures he took of the presenters and went over some of the highlights of the research being done by doctors and researchers from the U.S. and Europe. The next support group meeting will be held in late January or February 2011.

ILLINOIS

In October, the Chicago area group (including southeast Wisconsin) hosted Dr. G. Wendell Richmond, a nationally recognized expert in primary immune deficiencies. Dr. Richmond, who is in private practice, is also an expert on asthma and other allergic diseases. It was the first time that

Dr. G. Wendell Richmond explains the complexities of the immune system.



Support Group News, cont. on page 22

an immunologist presented to the group and everyone enjoyed his detailed presentation along with a lengthy question-and-answer period. A special thanks to Dr. Richmond for sharing his Saturday afternoon. The audio of his presentation is available from the IWMF WebEx account. If interested, contact **Don Brown** at ldonbrown@msn.com. At the next educational meeting 9 April 2011, Dr. Stephanie Gregory, Director, section of hematology, Rush University Medical Center at Rush University, will make a presentation on WM. She has spoken at many lymphoma conferences and has a very good understanding of our unique disease. Everyone is welcome.

MICHIGAN

About 20 members gathered in October for a potluck lunch. Group member **Dr. Jacob Weintraub**,who had attended the IWMF Educational Forum in Las Vegas, shared his impressions and the information that he had gathered there. Our next meeting is planned for the spring, most likely in April or May.

NEVADA

The group met in the fall to view the popular Ask the Doctor DVD from the 2010 IWMF Ed Forum and to share updates on individual WM journeys. The small, close-knit group meets three to four times a year, sometimes for lunch, on other occasions for meetings in the offices of the local Leukemia & Lymphoma Society (LLS).

NEW YORK

Two patient forums punctuated the fall. On 5 November the LRF held its annual meeting at the Brooklyn Marriott cosponsored by the IWMF. Dr. Richard Furman of Weill-Cornell presided over the WM breakout sessions. The number of group members attending the LRF event has grown each year to an impressive 50 this fall. As if this were not opportunity enough, the very next weekend the IWMF NYC area support group (along with the Connecticut and Philadelphia groups) had the good fortune of having both Dana-Farber's Dr. Steven Treon and Dr. Owen O'Connor of NYU Medical Center each present for an hour on various aspects of WM. The presentations were followed by more than an hour of questions and answers. Dr. Treon presented an update of the talk he gave at the Sixth International Workshop on WM in Venice. Dr. O'Connor discussed genes, including the very exciting search for "epigenetic therapies" that target "master regulator" genes in the hope of turning genes off and on, including those that prevent cancer cells from dying.

Mitch Orfuss is the In-coming support group leader in New York.

In 2011 **Mitch Orfuss** will take over from long-time group leader **Neil Massoth.** Mitch, our *Torch* IWMF-TALK correspondent, is a WMer himself and writes that he is "61, have (weirdly) always lived in New York City, had a long career in advertising and as a marketing instructor to grad students at night on the college level, am addicted to indoor rowing and non-fiction, and have been married (two accomplished children in college) for 24 years to a courageous woman who underwent a so-far successful stem-cell transplant after an unexpected diagnosis of acute myeloid leukemia in 2008."

Northeastern NY/Western New England

Business items opened the agenda of the late fall meeting held at the new American Cancer Society's HOPE CLUB (formerly Gilda's Club), notably the schedule for 2011 dates and programs: 5 February (Rituxan forum), 26 March (restaurant outing), 21 May (speaker), 6 August (picnic), 17 September (speaker), and 5 November (health insurance forum). The format for forum and speaker meetings will be similar: the group will view a DVD on the selected topic or hear the speaker, followed by a group discussion on the issue. Meetings will begin twenty minutes before the formal program to allow time for pre-meeting individual conversations. After the formal program, the group shares a potluck lunch – the most recent lunch concluded with group member **Katy Palermo's** memorable cheese cake.

EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

A fall pot-luck dinner and informal group sharing brought members together at the home of **Marcia** and **Glenn Klepac**. The group discussion started off on a nutrition theme as the group reviewed Dr. Andrew Weil's new anti-inflammatory food pyramid and sampled healthy food choices – edamame, mushroom crisps, roasted pumpkin seeds, hummus, and more. Conversation then turned to a lively discussion of WM as most members in attendance were currently undergoing or had recently completed therapy. Hot topics included the unpredictability and diversity of WM, IgM flare with Rituxan, and treatment-limiting side effects–such as Velcade-induced pain, low blood counts, and lung issues. The challenge of maintaining a good working relationship among patient, WM expert, and local oncologist elicited much interest and will certainly be continued at future meetings. Dinner followed with all sticking around for dessert – irresistible apple dumplings and ice cream by **Shari Hall**. The group looks forward to meeting again in early spring shortly after the WM Summit in Orlando.

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Support Group News, cont. from page 22

The November meeting of the SE and central Pennsylvania support group. From left to right are: Mike Eshleman, Jack Kiviat, Dr. Jim Yeager, Terrie Eshleman, Linda Morrow, Kay Anderson, Rita Ziats, Betty Wilt, Don Wolgemuth, Kate Wolgemuth.

WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY

For the fall meeting in the offices of the LLS, the group chose to view the Skywalk and Gala Reception DVD from the 3rd International Patient and Physician Summit as it presents such an optimistic outlook for those living with WM (both patients and caregivers). IWMF board member **Dr. Guy Sherwood** attended and held an impromptu question-and-answer session.

PENNSYLVANIA

Central and Southeast PA and Northern MD

New member **Jack Kiviat** joined the group at their November meeting at Messiah Village. A Thanksgiving mood prevailed while members related their latest treatments and status and expressed – as so many have over the years – that they see their illness as a gift, allowing them to reexamine their lives and take joy in each day. The sharing of experiences allows everyone to learn more about each other and to be aware of potential problems concerning various symptoms. The next meeting will be Sunday 13 February 2011 at Messiah Village from 2 to 4 pm in the Board Room.

Philadelphia

The Philadelphia group met in October to watch the Ask the Doctor DVD from the 2010 Ed Forum. There was only time to view the first half of the session because a group discussion followed each question, an innovative and valuable way to 'bring home' the information provided on the DVD to the group's individual members. In addition, time was reserved for homemade cake and casual chitchat. Heidi, playing the important role of mascot, enjoyed this time the best. At the following meeting, in December, Dr. Edward Stadtmauer, Professor of Medicine and Director of the Bone Marrow and Stem Cell Transplant Program at the University of Pennsylvania, spoke about Waldenstrom's – its symptoms, diagnosis, and treatments. He then fielded questions from the group. He was an excellent speaker and is the oncologist for some members of the group. The next meeting will be 13 February – if it doesn't snow.

SOUTH CAROLINA

Columbia

The South Carolina WM support group held a meeting in early December at the Palmetto Health Baptist Hospital in Columbia, SC. A representative from the SC chapter of the LLS briefed us on the types of support WM patients can receive from the LLS, including financial support. As in all of our past meetings, we enjoyed the opportunity to socialize with one another and share our experiences. The next meeting will be held in the May or June timeframe with details to be provided later.

TEXAS

Houston

The group will host Dr. Maria Scouros, Director of the Houston Cancer Institute on Sunday, 25 January, at 21 Briar Hollow Lane, in the Briar Room. The meeting starts at 2:30 pm and Dr. Scouros will begin her presentation "Understanding Your Cancer Treatment Options" at 3 pm. Refreshments will be served. This meeting is free and open to families, caregivers, and WM patients.

WASHINGTON

The Washington group welcomed several new members when it met on a Saturday afternoon in November for a time of sharing, interaction, and discussion of some of the "Ask the Doctor" questions from the Las Vegas forum. The next meeting is tentatively scheduled for 5 March. Group members

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Waldenström France members framed in the arches of the Institution Robin, a 13th century landmark in Vienne. Dr. Olivier Tournilhac stands sixth from the left.

John and **Kristen Jenson** (Kristen has served as secretary for the Washington group) are moving to Richland in eastern Washington where they would like to start a support group for those east of the Cascades. Interested people can contact Kristen at kristen@jensonfamily.org.

THE INTERNATIONAL SCENE

EDITED BY PENNI WISNER

FRANCE: Waldenström France Meets in Vienne

It rained almost everywhere in France on 18 September 2010, but not in Vienne, at the Institution Robin St. Vincent de Paul where Waldenström France welcomed patients and families. To prove it, sunbeams fill photographs of the event. This year, Dr. Olivier Tournilhac of CHU de Clermont-Ferrand presented his approach to the understanding and treating of Waldenström macroglobulinemia and answered the participants' many questions. Not only does he pursue his own interest in basic and clinical research, but Dr. Tournilhac strongly believes in educating his patients as well so they can participate in the management of their condition. In his fascinating talk, Dr. Tournilhac delved deeply into the current research and the insights it has generated. His detailed explanations were greatly appreciated by the attendees. **Michel Houche**, president of Waldenström France, personally oversaw the quality of the gastronomic breaks. As a consequence, the food was excellent both during the day and at the dinner in the evening, enhancing a very friendly environment. Next year the annual WM France patient-doctor meeting is planned for September 2011 in Paris.

SUPPORT GROUP LEADERS TALK LIST

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

IWMF SUPPORT GROUP CHAPTER LISTINGS

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

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

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

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

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

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

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

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

Sacramento/
San Francisco Bay Area
Alyce & Terry Rossow
925-447-8881
Rossow@ieee.org

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

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

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

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

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

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

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

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

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

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

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

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

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

HAWAII
(November – April)
Sandy Skillicorn
808-891-2882
jLsLs@aol.com

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

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

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

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

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

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

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

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

Judy Christensen
781-335-5698

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

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

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

MISSOURI
Northwestern (KC Area)
Karen & Joe Davis
785-266-0121
karenjdavis@gmail.com

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

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

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

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

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

Judy Christensen
781-335-5698

Western MA, VT & CT
Mel Horowitz
518-449-8817
wmcure@yahoo.com

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

NEW YORK
Northeastern NY/
Western New England
Mel Horowitz
518-449-8817
wmcure@yahoo.com

New York City
Mitch Orfuss
212 831-1306
morfuss@aol.com

Syracuse/Rochester/Buffalo
and Surrounding Areas
Stephen E. French, Sr.
585-621-3317
sfrench@rochester.rr.com

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

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

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

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

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

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

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

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

Jules Auger
503-746-7990
j.auger@comcast.net

IWMF SUPPORT GROUP CHAPTER LISTINGS

PENNSYLVANIA
Harrisburg
Terrie Eshleman
717-665-7393
tmesh74@ptd.net

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

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

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

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

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

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

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

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

TEXAS
Dallas
John Knutson
972-726-7790
johnknutson@tx.rr.com

Steve Pine
214-244-5515
iwmf4steve@verizon.net

Houston
Barbara & John Manousso
713-840-0828
wm@manousso.us

TEXAS (cont.)
Western
Regional Contact:
Bill Bilbro
575-642-4987
wbilbro@gmail.com

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

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

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

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

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

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

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

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

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

INTERNATIONAL SUPPORT GROUPS AND CONTACTS

AUSTRALIA
Gareth Evans
WMozzies-owner@yahoogroups.com

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

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

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

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

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

Ottawa
Jan Jones
613-722-2385
janellejones@rogers.com

CANADA (cont.)
Janet Cherry
613-596-1413
janet.parcher.cherry@sympatico.ca

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

Vancouver
Charlene Kornaga
250-474-7011
dennischarlene.kornaga@shaw.ca

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

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

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

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

GREECE
Alexia Kapralou
+30 210 6858574
kapralou_alexia@hotmail.com

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

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

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

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

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

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

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

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

Sussex
Mike Dewhirst
mkdewhirst@yahoo.co.uk

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

THE LIFELINE

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

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

TREATMENTS

ALLOGENEIC STEM CELL TRANSPLANTS

Eileen Sullivan 617-625-6957
ebsullivan27@comcast.net

2-CdA (CLADRIBINE) WITH RITUXAN

Bernard Swichkow 305-670-1984
theswichkows@aol.com

Brent Wingett 805-466-2345
bwingett@charter.net

BORTEZOMIB DEXAMETHASONE & RITUXIMAB (BDR)

Joe Gallo 941-493-1809
galljocon@verizon.net

Ron Linford 865-657-9895
rongl@aol.com

CHLORAMBUCIL

Janice Stein 415-346-6620
janicemstein@aol.com

CRYOGLOBULINEMIA

Fay Langer 904-625-3135
fhlanger@gmail.com

FLUDARABINE with cyclophosphamide (Cytoxan)

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

FLUDARABINE with Rituxan

Marty Kopin 310-390-1546
mkopin@yahoo.com

Jerry Block 301-460-9799
Jblock35@comcast.net

Eileen Sullivan 617-625-6957
ebsullivan27@comcast.net

ORAL CYTOXAN

Lou Birenbaum 314-961-5591
lbirenbaum@aol.com

PLASMAPHERESIS

Fred Bickle 805-492-4927
Flb134@msn.com

RAD 001

Tom Howenstine 419-542-8921
Howen978@verizon.net

R-CVP

Allen Weinert 360-683-3495
anweinert@gmail.com

(revlimed) LENALIDOMIDE

Christopher Patterson 617-632-6285
christopher_patterson@dfci.harvard.edu

RITUXAN

James Townsend 352-376-3664

Allen Weinert 360-683-3495
anweinert@gmail.com

SPLENECTOMY

Kathleen Ugenti 631-470-0971

Patricia McCue .....239-348-3456 winter
802-468-5779 summer

STEM CELL TRANSPLANT

Howard Donley 307-587-3397
donleyh@tctwest.net

THALIDOMIDE

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

VELCADE

Jeff Atlin 905-707-5640
jeffatlin@hotmail.com

SPECIALTY TOPICS

CAREGIVING

Lynn Bickle 805-492-4927
Flb134@msn.com

Brad Alexander 972-529-2002

CLINICAL TRIALS

Tom Hoffmann 501-868-8305
Thh97@msn.com

Guy Sherwood 765-282-4377
guysherwood@comcast.net

HEARING IMPAIRED TTY FACILITY

Betty McPhee 647-348-7440
bjmcphee@hotmail.com

NEWLY DIAGNOSED

Guy Sherwood 765-282-4377
guysherwood@comcast.net

Sallie Moore 516-795-3746
Smoore6042@aol.com

SOCIAL SECURITY DISABILITY

Howard Prestwich..... 815-233-0915
prestwic@mwci.net

WATCH AND WAIT

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

Renee Paley-Bain 203-744-7851
paleybain@aol.com

YOUNG WM

Nobby Riedy 650-879-9104
knobby@wildspaces.net

Bob Bailey..... 770-664-8213
Laurabailey64@gmail.com

INTERNATIONAL

BELGIUM

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

DUTCH SPEAKER

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

FINNISH SPEAKER

Veikko Hoikkala
veikko.hoikkala@dnainternet.net

FRENCH SPEAKER

Guy Sherwood 765-282-4377
guysherwood@comcast.net

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

FRENCH LANGUAGE TALK LIST

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

GERMAN SPEAKER

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

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

GERMAN LANGUAGE TALK LIST

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

SPANISH SPEAKER

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

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

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

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

SPANISH LANGUAGE TALK LIST

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

SWEDEN/NORWAY

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

NORDIC COUNTRIES TALK LIST

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

UNITED KINGDOM LIFELINE

2Cda (CLADRIBINE)

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

FLUDARABINE

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

FLUDARABINE AND RITUXIMAB

Mike Dewhirst
dewhirst_6@hotmail.com

OPTHALMOLOGY

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

PLASMAPHERESIS

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

RITUXAN

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

UK SUPPORT GROUP ONLINE FORUM

Raphael Altman
raltman@btinternet.com

CANADA LIFELINE

CLINICAL TRIALS

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

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

TTY- HEARING IMPAIRED

Betty McPhee (Toronto, ON)
bjmcphee@hotmail.com

Fluent in American Sign Language

NEWLY DIAGNOSED

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

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

WAIT & WATCH

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

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

CVP/RITUXAN

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

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

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

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

FLUDARABINE

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

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

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

RITUXAN

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

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

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

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

STEM CELL TRANSPLANT

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

VELCADE

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

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

VETERANS

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

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

SINCE SEPTEMBER 2010, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

In memory of Freddy Bastin:
Nicole Bastin

In memory of Dr. John C. Bernloehr:
Grand Ledge Counrty Club

In memory of Herbert Bisol:
Rick & Iris Park

In memory of Dr. Blythe Brown:
The Brown Family
Stephen & Caroline Brown
Debbie Bruckner
Roger & Deborah Close
Bryan & Margaret Cummings
Noranne Dicken
Dr. Andrew Dottridge
Graham & Marilyn Hannay
Mary Jones
Dr. Brian Liggett
Lois Milne
Craig Saloff
Betty Schultz
Sam & Alice Scultz
Adam Skulsky
Marina Skulsky
William Skulsky
Harold Tipper

In memory of Joe Burke:
Dominick Minni
Marcia Sachs
Stephanie Schmidt

In memory of Donald Burnett:
Jean & Dick Heinz

In memory of Desmond Cherry:
Rita Cherry
Ethel McKnight

In memory of Terry Cherry:
Rita Cherry

In memory of Jay Chamberlin Curtis:
Courtney Babic
Mary Bess & Buck Call
Martha Campbell
Chapter JO, PEO Sisterhood
Bruce & Jody Hoskins
Pat Neis
Bill & Marybeth Peden
Allan & Carla Price
Industry Relations Team - Matt Duncan, Allyson Estes, Jennifer Hood, Jason Jager, Amy Lee, Tori Morandi, Danielle Omega, Howard Polirer, and Leah Ward
Mr. & Mrs. Richard Wilson

In memory of Andrew Davare:
Marcia Stone

In memory of William George Faulkner:
David Gottlieb

In memory of Jerry Fleming:
William Bass

In memory of Mary Susan Hennesy:
Mark Scaglione

In memory of Doris Katz:
Mal & Judy Roseman

In memory of Robert Kilgour:
Peter Hosey

In memory of Judy Kliever:
Suzanne Herms
Marilyn Stolfa
Stephanie Waxman
Nancy & Ken Witthaus

In memory of Bert Franklin Lee:
Marge Kline
Rick & Judy McCauley
Kevin & Laura Tyburski

In memory of Don Lindemann:
Connie & Joe Anderson
Catholic Charities of the East Bay – Project ACCESS CCEB Staff
John & Sherry Diestler
Joe Fox & Lia Lent
The Frey Family
Teresa Hager & Lee Milligan
Sue Herms
Sonia Jacques
Kathi Jordan
Helen Kalkstein
Robert & Charlene Kyle
Karen Platt
Alice Riginos
Heather & Stan Rotz
Anne Severs
Frank & Louise Snitz

In memory of Judith Ann Longino:
James Carns

In memory of Anthony Mauer:
Boyce, Spady & Moore, PLC
Harold C. Brown & Co., LLC

In memory of Marge Mellon:
Jeffrey & Marge Beder
Helene & Neil Levin
Janet Saevitz

In memory of Earl S. Morrison:
Mildred Morrison

In memory of Lynne Murphy:
Tracy Brown

In memory of Marty Rozenman:
Carol Blazer
The Dublin Chamber of Commerce
Maureen Fertig
Jeff & Melisande Heckman
Ray & Patty Kennedy
Kathleen L. Radcliff
Nancy Rubenstein
Janet Watters

In memory of Robert Malcomb Semmes:
David & Maureen Timberlake

In memory of Betty Sorte:
James & Marjorie Alley
Dan & Sue Bloomdahl
Wilma Boggs
Fred & Margaret Brems
Buff Cooke
Jayne Freeman
Ray & Elaine Johnson
Marjorie Mack
The McNeill Group
Thomas & Mary Penn
Margaret Anne Spindler
Lexie Stremel
Eleanor J. Swansen
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In memory of Betty Timbs:
Tom Keener

In memory of Charles Vassallo:
Serina & Brad Dansker
Liz Lawton

In memory of Harry Vaughan:
Linda Vaughan

In memory of Joan Vorbach:
Mr. & Mrs. James & Maureen Brolly
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In honor of Elizabeth Crawford:
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Macroglobulinemia Foundation
3932D Swift Road
Sarasota, FL 34231-6541

Telephone 941-927-4963 • Fax 941-927-4467
E-mail: info@iwmf.com. • www.iwmf.com
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