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INSIDE THIS ISSUE

DOCTOR ON CALL: GIAMPAOLO MERLINI, M.D.

Amyloidosis Associated with Waldenström Disease or IgM-MGUS

Dr. Giampaolo Merlini

Dr. Giampaolo Merlini of the Amyloidosis Research and Treatment Center, Foundation IRCCS Policlinico San Matteo, Department of Molecular Medicine, University of Pavia, Pavia, Italy, is a world authority on amyloidosis. While IgM amyloidosis occurs infrequently in Waldenstrom's macroglobulinemia patients, it is a serious complication and one that every Waldenstrom's patient needs to be aware of.

What is amyloidosis?

Proteins are the engine of life in all living organisms. In order to function properly, proteins need to be assembled, or folded, in the right way. We now recognize almost 30 proteins that are, or may become, "misfolded" and "sticky" through aging or through mutations and form aggregates that are toxic for tissues, causing severe and progressive organ dysfunction. These aggregates of misfolded and sticky protein can then organize into very fine needles, called fibrils, which deposit and accumulate in organs and further impair organ function. These fibrillary deposits have a fatty-like appearance and are called amyloid, hence the term amyloidosis to indicate the diseases characterized by such deposits. For instance, one of these proteins, called beta-protein, which is produced in the brain, can aggregate and form plaques of amyloid deposits causing progressive loss of the brain cells (neurons) and of the cognitive functions as observed in Alzheimer's disease.

The amyloid associated with WM and IgM-MGUS is the result of misfolded proteins from the immune system produced in the following manner. Some of the cells involved in the body's defense, namely the B-cells and the plasma cells, generate proteins referred to as antibodies or immunoglobulins that are constructed against ever-changing targets, including bacteria, viruses, toxins, etc. To continuously adapt our defenses against such new threats, the structure of an immunoglobulin needs to be modified. Modification of an immunoglobulin is accomplished by mutation.

Each immunoglobulin is composed of two heavy chains and two light chains that are bound together to form a structure capable of recognizing specific targets. The engineering of these immunoglobulins depends on very sophisticated cellular mechanisms and requires the production of an excess of light chains that can be released in the blood as free light chains. In rare cases, the mutations required for tuning the body's defenses may result in light chains that have an altered structure or misfolding. Such misfolded proteins become sticky and toxic, and they accumulate in different body sites as amyloid deposits, ultimately leading to dysfunction of vital organs. This type of amyloidosis is named light chain amyloidosis (AL), also known as primary amyloidosis. AL or primary amyloidosis is the most common form of the amyloidoses that affect several organs (referred to as systemic amyloidoses), with approximately 10 new patients per million per year.

How frequently is amyloidosis associated with Waldenström macroglobulinemia or with IgM-MGUS?

AL amyloidosis can complicate Waldenström macroglobulinemia and IgM-MGUS. This occurs when the free light chains produced by the lympho-plasmacellular clone, which underlies both WM and IgM-MGUS, turn out to be misfolded. However

Doctor on Call cont. on page 2

Doctor on Call cont. from page 1

this is an uncommon event, and in fact IgM-associated amyloidosis represents only 5 to 6% of all cases of AL amyloidosis, with a yearly expected incidence of 0.6 cases per million. On the other hand, when an IgM-associated amyloidosis arises, it may become necessary to modify the treatment and monitoring of the underlying disease. Therefore the possibility of developing an IgM-associated amyloidosis should always be taken into account when monitoring patients with Waldenström macroglobulinemia or IgM-MGUS.

The IgM-associated amyloidosis presents distinct features when compared to non-IgM associated amyloidosis: 1) the concentration of the circulating free light chains is lower, 2) the heart is less frequently and less severely involved, and 3) the amyloid is frequently localized in the lung and in lymph nodes.

When should one suspect the presence of amyloidosis?
Primary amyloidosis can target practically all organs, except the brain. The kidney is involved in two-thirds of amyloidosis patients, characterized by loss of proteins in the urine, which becomes foamy, by swelling of the legs, and by eventual damage to the purifying function of the kidney. The heart is involved in almost half of the patients who develop shortness of breath during their usual activities, difficulties in climbing the stairs, fatigue, low blood pressure, and swelling of the legs. The nerves are affected in more than one quarter of patients, with tingling, numbness, burning, loss of sensitivity to hot or cold at the feet and legs, and, as the neuropathy progresses up to the knee, it may extend to the arms starting from the fingers. The amyloid can also damage the autonomic nervous system that regulates certain functions, such as bowel movements and erectile function in men, resulting in diarrhea or constipation and impotence. The lung and the upper respiratory passages can be involved by amyloid deposits with possible obstruction of the airways and reduced blood oxygenation contributing to shortness of breath. In one-fifth of patients, the lymph nodes can slowly become enlarged because of the amyloid deposition. The tongue can also become enlarged and stiff and show tooth impressions. Amyloid deposits in the liver can cause enlargement of the liver with possible compression of the stomach and loss of appetite. In a few patients, the amyloid deposits in the blood vessels make them fragile with easy bruising and purple spots that vanish in a few days, particularly around the eyes and at the base of the neck.

As described, the clinical manifestations are very diverse and can mimic common conditions in the elderly, such has cardiac failure or kidney and nerve dysfunction in patients with diabetes, making amyloidosis a difficult entity to be recognized. This holds especially true for amyloidosis associated with Waldenström macroglobulinemia, since

Doctor on Call cont. on page 3

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Doctor on Call cont. from page 2

some manifestations of amyloidosis are already part of the clinical picture of Waldenström macroglobulinemia (for example fatigue and shortness of breath due to anemia or peripheral neuropathy due to the antibody activity of the IgM versus certain components of the nerve tissue). Therefore patients and physicians should be especially alert in order to detect promptly any clinical manifestations possibly related to amyloidosis.

Is it possible to diagnose the presence of amyloid early, before severe organ damage has occurred?

Most of the clinical manifestations described above appear when the damage to the target organ is already advanced and sometimes irreversible. Manifestations of nerve involvement may appear rather early, but the heart (the most crucial organ on which our survival depends) and the kidneys are usually damaged silently until they become unable to function properly and become symptomatic. Fortunately, we can monitor both the heart and kidney functions using widely available biomarkers that can detect promptly the damage caused by the amyloid process, even several months before the appearance of symptoms. When the heart is stressed, it produces a hormone called "B natriuretic peptide" (BNP) and its fragment called NT-proBNP, which we can measure in the blood. It is now well established that these markers are extremely sensitive to cardiac amyloid infiltration, which they can detect in the very early stage, even though the markers can also be indicative of other primary cardiac diseases, such as atrial fibrillation or coronary disease. We would recommend that BNP or NT-proBNP be measured at least once a year, particularly in individuals with IgM monoclonal protein and high levels of free light chains in the blood with an abnormal free light chain ratio. If the level of these biomarkers is elevated, a careful evaluation by a cardiologist and echocardiography can help to detect possible early amyloid cardiac damage. Effective therapies can then be started promptly. Kidney involvement can be detected early by measuring both the level of albumin in the urine and the level of serum creatinine and then estimating the creatinine clearance by employing an established formula. These measurements should also be performed at least once a year in individuals with a serum monoclonal IgM.

In the presence of clinical manifestations or increased level of cardiac and renal markers indicating the possible presence of light chain amyloidosis, rather simple diagnostic procedures should be promptly pursued. Since amyloidosis is characterized by the deposition of fibrillar protein, the diagnosis relies on the documentation of such deposits in tissues. The most accessible tissue is the fat around the navel that can be easily and painlessly aspirated using a fine needle. Specific staining can document the presence of the amyloid deposits in almost 90% of patients. In the remaining 10% who do not show deposits but have the disease (false negatives), it is possible to search for deposits using a biopsy of the labial salivary glands that identifies amyloidosis in an additional 5% of patients. Certain clinical centers may use rectal biopsy, and that is also useful. If all these biopsies are negative, while the clinical suspicion of amyloidosis is strong, then it is possible to biopsy the affected organ, usually the kidney or the heart.

Once the amyloid deposits have been documented, it is important to make sure that they are formed by light chains in order to institute the appropriate treatment. As reported above, a significant number of proteins can form amyloid deposits. For instance, in rare cases (approximately 5%) of patients with Waldenström macroglobulinemia, the amyloid deposits are not formed by light chains but by another protein called serum amyloid A (SAA) that increases markedly in the blood when there is a chronic inflammation. This type of amyloidosis (reactive or secondary amyloidosis) requires a distinct therapeutic and monitoring approach. Furthermore, in an elderly patient with isolated cardiac involvement and an IgM spike, it is wise to exclude amyloidosis related to aging (senile systemic amyloidosis) since it requires a different therapy. If the cardiac involvement is associated with involvement of the peripheral nerves, familial amyloid polyneuropathy (FAP) should be excluded. The determination of the type of protein constituting the amyloid deposits requires a specialized approach by amyloid referral centers, and your doctor should guide you in this process.

Is amyloidosis treatable?

Light chain amyloidosis is a treatable disease, with impressive survival benefit in responding patients. The most effective therapy, at present, is the suppression of the synthesis of the misfolded monoclonal light chains through anti-clonal chemotherapy; hence the therapies used for Waldenström macroglobulinemia are also effective for the treatment of this severe complication. In the presence of amyloid, however, rapidly acting agents are preferred since it is vital to suppress the production of the toxic light chains as soon as possible. The intensity of the therapies may be limited by the presence of heart dysfunction caused by amyloidosis. In relatively young patients without significant heart damage, autologous stem cell transplantation may be considered. Treatment should be carefully monitored with frequent evaluation of the level of serum free light chains and of markers of heart (using NT-proBNP) and kidney (using urinary albumin level and serum creatinine) function.

In patients who achieve complete suppression of the amyloid light chains and improvement in the level of cardiac or renal biomarkers, survival is greatly extended. It is very important to sustain the function of the damaged organs with supportive therapy while chemotherapy is producing its beneficial effects. Coordinated collaboration of specialists is necessary to provide the best possible supportive care. Cardiologists

Doctor on Call cont. on page 4

Doctor on Call cont. from page 3

and nephrologists know that patients with amyloidosis require particularly careful supportive measures. In patients with low blood pressure upon rising, the use of diuretics and antihypertensive drugs requires caution. The pain caused by the nerve involvement can be controlled by using pain medication. In patients who achieve a complete and durable response to chemotherapy but with end-stage renal failure, kidney transplantation may be considered.

What are the novel treatments for amyloidosis?

Although novel agents combined in chemotherapy regimens that are both rapid and effective have greatly improved the treatment of primary amyloidosis and significantly extended the rate of survival, the outcome is still suboptimal in most patients. Intense research is ongoing to develop new treatment approaches, targeting, for instance, the amyloid deposits and promoting their resorption by clearance mechanisms of the body. Several research groups are focusing on the mechanisms of cardiac damage by toxic light chains in order to identify new therapeutic avenues that may reduce cardiac toxicity and accelerate recovery of heart function. It is expected that such novel remedies will soon be synergistically combined with anti-clonal therapy to further improve care for patients and possibly cure this complex but treatable disease. The key to improving the care of amyloidosis is early diagnosis followed by prompt, effective therapies. The widespread use of biomarkers may facilitate the early detection of organs damaged at an early stage of this disease and lead to their full recovery.

Dr. Merlini holds the rank of Professor in the Department of Molecular Medicine, University of Pavia, Italy. He is the Director of the Amyloidosis Research and Treatment Center of the University Hospital Policlinico San Matteo, Pavia. Dr. Merlini was trained in clinical and laboratory investigation of monoclonal gammopathies by Prof. Jan Waldenström (Lund University, Sweden) and by Prof. Elliott Osserman (Columbia University, NY). His main research interests are the pathogenesis, natural history, and treatment of various monoclonal gammopathies and of systemic amyloidoses. His research interests focus on the development of new diagnostic approaches, of reliable biomarkers for assessing prognosis and response to therapy, and of novel medicines for the treatment of lympho-plasmacellular disorders and systemic amyloidoses. Past President of the International Society of Amyloidosis, on October 18, 2008, in Stockholm, Dr. Merlini was presented with the Waldenström's Award in recognition of his contributions to the scientific understanding of Waldenström's macroglobulinemia. Dr. Merlini can be contacted at: gmerlini@unipv.it

NEW INITIATIVE FOR NAMED FUNDS

The IWMF Board of Trustees announces a new initiative for Named Funds, both Current and Endowed.

Current Named Funds require a commitment of $50,000 or more and can be funded over five years. These Named Funds will be drawn on as needed to support the IWMF Research Fund or Member Services Fund.

Endowed Named Funds require a commitment of $250,000 and may be funded during the donor's lifetime or through the donor's estate. An Endowed Named Fund will distribute interest earned to the IWMF Research Fund and/or the Member Services Fund, as designated by agreement with the donor.

The following individuals have established Current Named Funds that are funded at a level of $10,000 - $50,000 per year:

Thomas M. Baker Research Fund
In honor of Thomas M. Baker by Frederick & Almie Baker

L. Michael and Rosalie Larsen Research and Member Service Fund
Mike & Rosalie Larsen

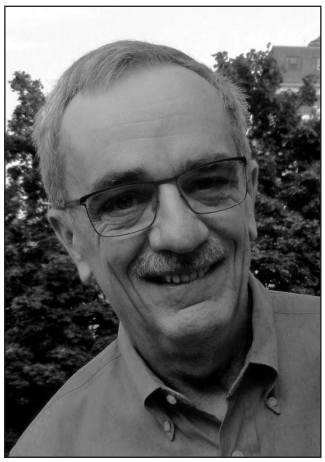
Caroline and Harry McPherson Research Fund
In honor of Harry McPherson by Samuel Schneider Foundation

Carolyn K. Morris Research Fund
In memory of Carolyn K. Morris by Maynard Morris

Anonymous donors have established an Endowed Named Research Fund to be funded through their estate at a minimum of $250,000.

We wish to thank these initial supporters for helping us launch this new program! If you are interested in setting up a Named Fund in memory or in honor of family member, friend, medical professional, or to support a service such as the *Torch,* please contact Dave Benson at 952-837-9980 or *dave@dbenson.com.*

PRESIDENT'S CORNER



Thank goodness it's spring! Like the flowers that will soon be popping up around here in Philadelphia, the IWMF has plenty of exciting new developments popping up and worth celebrating:

• The FDA's decision to grant Breakthrough Therapy Designation for the investigational agent ibrutinib as treatment for WM and for relapsed or refractory mantle cell lymphoma (MCL). The participation of your fellow WMers in clinical trials played a crucial role in this important advancement in the development of therapy for WM. To learn more about this major advance, see the summaries of the most recent research reports on ibrutinib in Medical News Roundup on page 8. The IWMF press release on page 6 announces that Waldenstrom's macroglobulinemia is one of two cancers approved for ibrutinib by the FDA's designation of Breakthrough status for this drug.

• The IWMF Educational Forum in San Diego from May 17-19. If you haven't registered, there's still time. Come hear the latest developments in WM including ibrutinib, all focused around our theme of *Imagine a Cure*.

• The availability of downloadable materials from the IWMF website. Do you need a copy of *Waldenstrom's Macroglobulinemia: Treatment Options* or *Waldenstrom's Macroglobulinemia: Questions & Answers* or other IWMF materials? Just go to our website *(iwmf.com/publications/)*, enter your information, and you'll have what you need in seconds. This is a great way to get what you need while saving the IWMF the cost of printing and mailing. However, if you prefer a hard copy, we'll mail it to you.

• The news that Tom Myers and the IWMF Research Committee worked with our Canadian colleagues at the Waldenstrom's Macroglobulinemia Foundation Canada (WMFC) and the Leukemia & Lymphoma Society to fully fund a new research project on mouse modeling with the MYD88 gene mutation from Dr. Ruben Carrasco of the Dana-Farber Cancer Institute. A great job in stretching our limited resources! And special thanks go to Arlene Hinchcliffe, President of WMFC, and the Canadian WMers!

• A new Member Services Matching Gifts program which enables you to double the impact of your giving from now until May 15. See page 11 of this issue or our website at *iwmf.com/docs/documents/2013_Matching_Gift_Program_Letter.pdf* for more information.

Would you like to make a unique gift for Mother's Day or Father's Day? Consider a Tribute gift. The amount you give will be doubled under the Matching Gifts program, the recipient will receive a letter from the IWMF acknowledging your donation, and the recipient's name will be printed in the next issue of the *Torch*.

• An increasing number of WMers are finding creative and fun ways to give to the IWMF, as reported on page 17. Doesn't this article give you some great ideas?

You've heard us say that the IWMF is volunteer-led and volunteer-funded. What does that mean? From the perspective of "hours spent on IWMF business," our office in Sarasota has a staff of 4—1 full-time and 3 part-time employees—who collectively put in about 5300 hours a year, the equivalent of 2 1/2 employees full time. (And the great service we get is a very efficient return for 5300 paid hours!)

We decided we wanted to know how many volunteer hours we received. We estimated the number of hours that IWMF Board members, support group leaders, Lifeline volunteers, the *Torch* staff, and committee members (Publications, Research, Fundraising, Information Technology) put in and came up with a total of 22,500 hours—the equivalent of 10.8 full time people. Or, put another way, we have over 4 times as many volunteer hours as paid hours. Now, that's volunteer-led! Thank you to everyone who tirelessly gives his or her time to the IWMF. Just think what we could do with 50,000 volunteer hours!

You, too, can support the IWMF by volunteering. Each and every WMer is critical to our success in conquering this disease. With a rare disease like WM, every person counts—especially you! How can you put your talents to work to help conquer WM?

Could you volunteer your time and skills to the IWMF? Ask your support group leader how you can help or call the IWMF office in Sarasota and tell us about your skills. We particularly

President's Corner cont. on page 6

President's Corner, cont. from page 5

need people with skills in fundraising for foundations, with skills in website and Internet technology, with editorial or writing skills. What skills can you offer?

Could you advocate for the IWMF within the medical community? This could be as simple as asking your doctor or nurse if their practice has other WM patients. If so, ask them to recommend the IWMF to their patients. Not everyone with WM is aware of the IWMF. You can do your part by "recruiting" your doctor as our ally. If your doctor is not on our mailing list, ask if he or she would like to be. If they are on our mailing list, they will receive the *Torch* and other informative materials. You can add your doctor to our mailing list by e-mailing contact information to Julie Jakicic at *office@iwmf.com* or by calling her at 941-927-4963.

Could you ask your friends and family to donate to the IWMF? With the Matching Gifts program, all gifts from new donors will be doubled. All Tribute and Memorial gifts will be doubled. Be creative: give a gift to honor your support group leader, your oncologist, a favorite nurse, your spouse, the IWMF office staff, or anyone who has made a difference in your life. Each and every Tribute or Memorial gift will be doubled between now and May 15th.

With all us pulling together, we'll have even more to celebrate in the future.

Hope to see you in San Diego!

Stay well,

Carl

PRESS RELEASE ISSUED BY THE IWMF ON FEBRUARY 21, 2013

FDA Expedites Potential New Therapy for Rare Lymphoma

Patients with a rare and incurable cancer called Waldenstrom's macroglobulinemia (WM) have a new reason for hope, thanks to the U.S. Food and Drug Administration's (FDA) decision to grant Breakthrough Therapy Designation for the investigational oral agent ibrutinib, developed as treatment for WM and for relapsed or refractory mantle cell lymphoma (MCL).

"This is a historic day for the WM community," stated Carl Harrington, President of the volunteer-led International Waldenstrom's Macroglobulinemia Foundation *(www.iwmf.com)* which is dedicated to WM disease research and patient support. "We are excited by the FDA's decision and by the joint commitment of Janssen Research and Development and Pharmacyclics to develop a treatment for our very rare disease that affects 3 per 1 million persons annually in the U.S." Tom Myers, IWMF Vice President for Research, added "We are proud of the WM patients who are currently participating in clinical trials of ibrutinib." Both Harrington and Myers are also patients.

This is an important advance in the development of therapy for WM, a rare and incurable type of B-cell lymphoma (http://www.iwmf.com/about-wm/index.aspx) for which no standard of care or FDA-approved treatment exists. It comes on the heels of another important development in WM – the discovery of a genetic mutation (known as MYD88 L265P) that is prevalent in almost all WM patients. The mutation was detected in research performed by Dr. Steven Treon and his group at the Dana-Farber Cancer Institute in Boston, MA, and funded in part by the IWMF. Dr. Treon's group has also discovered that the mutation impacts some of the same cellular pathways targeted by ibrutinib. "Without the impetus of advocacy for research, seed funding by the IWMF, and the dedication of top-notch researchers around the world working on our rare disease, this would not have been possible," said Harrington.

Breakthrough Therapy Designation is intended to expedite the development and review time for potential new medicines that can treat a serious or life-threatening disease and that demonstrate substantial improvement over existing therapies. It was signed into law on July 9, 2012, as part of the U.S. Food and Drug Administration Safety and Innovation Act (FDASIA). Since then, three drugs have achieved this status, with ibrutinib being the first approved for cancer treatment.

SHOULD I GET A SECOND OPINION?

BY MORIE A. GERTZ, M.D., M.A.C.P.

Whether an individual should get a second opinion for a medical condition is not a simple "yes" or "no" question. The answer is dependent upon the patient's level of trust and relationship with the physician, the level of confidence in the facilities of the associated medical center, plus the patient's understanding of the condition and the therapeutic options available.

There are many very well trained medical oncologists in practice who have received superb mentorship at large academic medical centers and who are extremely bright and facile in the management of malignant disease. Unfortunately, in most practices, Waldenström's macroglobulinemia constitutes no more than one-half of 1% of a general oncology practice. As a consequence, in most practices, a physician can be expected to see a patient with newly diagnosed Waldenström's every second or third year. This raises very unique issues for Waldenström's patients, issues that are not shared by patients with breast, colon, lung, prostate, or stomach cancer.

In the case of a disease with unique issues, there is no greater teacher than direct experience. I, myself, am extremely thankful to all the Waldenström's macroglobulinemia patients whom I have had the privilege to see and serve over the years because they have taught me more about the disease than anything that can be printed or written in manuscripts or textbooks. A reasonable metaphor to consider is as follows. How would you feel if a plumber came to your house, a problem was reported, and his response was: "I have never seen this type of hydraulic problem before, but I brought my plumber's manual with me to help me manage the situation." How comfortable would you be in this situation?

A similar example would be if you brought your car to a repair shop and you were told, "I have never seen this type of automotive problem before in my career, but I will read the manual, which should get me up to speed with the types of problems your car has had." Do you not owe it to yourself to treat yourself better than you would your car or your plumbing? Would you place your trust concerning a medical problem in an individual with no experience pertinent to the problem at hand?

Speaking personally, I would prefer to consult with someone who graduated in the middle of their medical school class but who had decades of experience with my problem than with someone who, while graduating first in their class, had no experience with the problem but committed themselves to learn as much as they possibly could about it. I would not choose this second option. I would not allow this to occur at my own expense. I think, in the situation where a practitioner has limited experience, it is reasonable to obtain a second opinion to help guide care.

There are other issues. In medical centers that have extensive experience with the disease, oftentimes research is actively ongoing. Being seen as a patient at a medical center may allow the biobanking of specimens such as blood and bone marrow that could be used for a better understanding of the disease itself. The finding of the MYD88 mutation was certainly derived from patients who were willing to allow research on their blood and bone marrow, thus leading to a breakthrough discovery applicable to all patients with Waldenström's macroglobulinemia. Therefore, it is relevant to ask whether the diagnostic testing that you are subjected to will benefit other patients or is simply being used as a diagnostic tool.

At medical centers where Waldenström's macroglobulinemia is infrequently seen, there may be no available treatment protocols designed by the best and brightest in the field to move outcomes to the next superior level. Being seen at a medical center that specializes in Waldenström's offers the potential for clinical trial participation that might in turn allow treatment with a brand new agent that is promising in Waldenström's or might allow treatment with new combinations of existing agents. Either way, the resulting outcomes are potentially better than at other medical centers that do not provide such options. These types of protocols are frequently unavailable at smaller medical centers because the cost of opening clinical trials where accrual numbers are expected to be small is an inefficient use of resources. It is, therefore, important to ask the oncologist whether they participate in a cooperative group and, if so, does this group offer the opportunity to participate in clinical trials or is the only available option the same therapy that has been used for the last decade.

There are other obvious considerations (the expense of travel, the difficulty of accessing a large medical center with expertise) that will influence the decision. IWMF-Talk, the Waldenström's talklist, contains many anecdotal reports of patients who went for a second opinion and were disappointed. Alternatively, quite a number of reports are recorded by those who were reassured by the fact that the treatment they were receiving was first-tier, who appreciated the opportunity to have a large medical center with expertise to follow along their disease course in the background. And who also appreciated the opportunity to establish a relationship with an expert in the disease that would allow access to new agents should the need be required.

Clearly, there is no "one size fits all," but, hopefully, this article helps with some of the pros and cons that an individual diagnosed with WM needs to address in making this important decision.

Dr. Morie A. Gertz is the Roland Seidler Jr. Professor and Chair, Department of Medicine, College of Medicine, Mayo Clinic, and Mayo Distinguished Clinician. In his clinical practice he has evaluated and treated patients with Waldenström's macroglobulinemia for more than thirty years. Dr. Gertz serves on the Scientific Advisory Committee of the IWMF.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE

Ibrutinib Receives Breakthrough Therapy Designation for WM – Ibrutinib, an oral inhibitor of Bruton's tyrosine kinase (BTK), was recently granted Breakthrough Therapy Designation by the U.S. Food and Drug Administration as single agent therapy for the treatment of WM and of relapsed/refractory mantle cell lymphoma. Breakthrough Therapy Designation is intended to expedite the development and review of new drugs for serious or life threatening diseases when preliminary clinical evidence indicates that the drugs may demonstrate substantial improvement over existing therapies. BTK is involved in regulating apoptosis (programmed cell death), adhesion, and cell homing and migration. Through these actions, BTK directs malignant cells to lymphoid tissues, providing an environment necessary for their proliferation. Ibrutinib was developed by Pharmacyclics and Janssen Biotech and specifically targets BTK; it first entered the clinical trials process in 2009.

Dose Escalation Study of Ibrutinib Reported – One of several studies of ibrutinib that led to its Breakthrough Therapy Designation for WM and mantle cell lymphoma was a multicenter U.S. trial reported by Dr. Ranjana Advani of Stanford University Medical Center. In this study, 56 patients with relapsed or refractory B-cell lymphoma and chronic lymphocytic leukemia received escalating oral doses of ibrutinib in two dosing schedules. Most adverse effects were of relatively low severity and self-limited. Dose-limiting events were not observed, even with prolonged dosing. Dose escalation continued to 12.5 mg/kg per day without reaching the maximum tolerated dose. The response rate was 60%, including a complete response rate of 16%, and median progression-free survival was 13.6 months.

Nimbus Reports Synergistic Effects of IRAK4 Inhibitors with Ibrutinib – Nimbus Discovery LLC presented pre-clinical data showing that its novel IRAK4 inhibitors (ND-2110 and ND-2158), when combined with ibrutinib, work synergistically to cause selective cell death in blood cancers with the activating MYD88 L265P mutation. This mutation is prevalent in WM patients, determined in studies first reported by Dr. Steven Treon at Dana-Farber Cancer Institute. The Nimbus findings were generated in collaboration with Dr. Louis M. Staudt at the National Cancer Institute. Nimbus expects to initiate clinical trials with these drugs in 2014.

Bendamustine Treatment Evaluated for AL Amyloidosis – A joint Italian-German study evaluated the safety and efficacy of bendamustine and prednisone in 36 patients with AL (amyloid light-chain) amyloidosis. Amyloidosis is a progressive incurable disease characterized by abnormal deposits of proteins in one or more tissues or organs. Ten of these patients (28%) had IgM clones, and 8 of the 10 also received rituximab with the bendamustine/prednisone therapy. The target dose of bendamustine was 100 mg/m^2, although lower doses were used in patients with cytopenias (reductions in the normal number or red blood cells, white blood cells, or platelets). Among the subjects with IgM clones receiving the treatment combined with rituximab, 6 patients (75%) responded. Overall, 33% of patients died, and 65% are alive after three years. The study concluded that bendamustine is effective and well tolerated and represents an additional treatment option in AL amyloidosis.

Chlorambucil Compared to Fludarabine in Phase III European Trial – A multicenter European study reported Phase III results of a randomized trial of chlorambucil vs. fludarabine for patients with untreated WM, marginal zone lymphoma, and lymphoplasmacytic lymphoma. Of the 414 patients enrolled, 339 had WM. The overall response rate was 47.8% in the fludarabine arm vs. 38.6% in the chlorambucil arm. With a median follow-up of 36 months, progression-free survival and duration of response were significantly improved in the fludarabine arm. In WM patients, median overall survival was not reached in the fludarabine arm. Grade 3-4 neutropenia was significantly higher and second malignancies were significantly lower with fludarabine than with chlorambucil. The study's conclusion was that fludarabine significantly improved progression-free survival compared to chlorambucil, and in patients with WM, it improved overall survival.

Researchers Study Nuclear Protein Expression in WM/LPL – Researchers at Northwestern University and the University of Chicago looked at the expression of nuclear proteins in WM/LPL (lymphoplasmacytic lymphoma) cells. In this study, the expression patterns of these proteins were analyzed in plasma cells and lymphocytes in 29 newly diagnosed patients. These patterns were compared to the expression profiles seen in normal bone marrow samples, reactive tonsils, and cases of multiple myeloma and marginal zone lymphoma. The percentage of plasma cells co-expressing CD138 and PAX5 was significantly higher in WM/LPL compared with benign tissues, marginal zone lymphoma, and multiple myeloma whereas the percentage of plasma cells co-expressing CD138 and MUM1 was lower in WM/LPL. The finding of relatively increased PAX5 expression and decreased MUM1 expression suggests that components of B-cell expression are abnormally persistent in WM/LPL plasma cells. This nuclear protein expression pattern could be an aid in the differential diagnosis of WM/LPL as well as a clue to disease pathogenesis.

New Experimental Treatment for Chemotherapy-Induced Peripheral Neuropathy Advances – DARA Biosciences, Inc., has submitted an Orphan Drug Application to the U.S. Food and Drug Administration for KRN5500, a treatment in development for painful and chronic chemotherapy-induced

Medical News, cont. on page 11

IWMF RESEARCH UPDATE

BY TOM MYERS, VICE PRESIDENT FOR RESEARCH

New IWMF Grants Awarded

The Waldenstrom's Macroglobulinemia Foundation Canada (WMFC) and the Leukemia & Lymphoma Society (LLS) have agreed to jointly fund the proposal of Dr. Ruben Carrasco of the Dana-Farber Cancer Institute to develop a mouse model with the MYD88 L265P gene mutation. The IWMF will play a supporting role in providing technical oversight of the project. See below for reports on continuing research on the MYD88 mutation and on mouse modeling previously funded by the IWMF.

In a new IWMF-supported research project, Dr. Kareem Azab at Washington University in St. Louis is studying "The Role of Hypoxia in the Dissemination of Waldenstrom's Macroglobulinemia." Hypoxia is a condition of low oxygen concentration. By exposing WM cells to low oxygen environments and then measuring their ability to move from one area to another, Dr. Azab has demonstrated that hypoxic conditions decrease the adhesion of WM cells to the bone marrow stroma (connective tissue) and increase their ability to migrate. He hypothesizes that hypoxia can thus cause WM cells to move to uninvolved areas in the bone marrow where oxygen is more plentiful. Dr. Azab will investigate the role of hypoxia in cell signaling and the identification of compounds affecting hypoxia.

IWMF-Supported Research in Progress

In 2011 the IWMF awarded a research grant to Dr. Steven Treon at the Dana-Farber Cancer Institute (DFCI) for a project entitled "Genomic Studies into Sporadic and Familial WM." Using whole genome sequencing, Dr. Treon's group demonstrated that over 90% of WM patients have a mutated gene designated MYD88 L265P. It was also determined that the mutated MYD88 gene was part of a signaling pathway containing several other components that affect the growth of WM cells. One of these components is designated as BTK (Bruton's tyrosine kinase). Pharmacyclics and Janssen Biotech have developed an oral agent called ibrutinib that inhibits BTK. This agent appears very promising in recently announced preliminary studies treating WM, and as a result the FDA has granted Breakthrough Therapy Designation to ibrutinib in order to expedite the development and review time for this drug. At this time there is no FDA-approved drug for treating WM.

Dr. Treon has submitted a grant request to the IWMF Research Committee to investigate the mechanisms whereby MYD88 L265P is involved in causing or controlling WM. This project would also study various agents that could affect the manner in which MYD88 reacts with proteins that influence the growth and death of WM cells. The grant request is currently under review.

With heightened research interest in MYD88, it becomes important to have cell lines and mouse models that exhibit this mutated gene.

The WM cell line projects supported by the Leukemia & Lymphoma Society (LLS) and the IWMF have been very successful. Originally four researchers working independently attempted to develop cell lines. Dr. Stephen Ansell at Mayo Clinic and Dr. Asher Chanan-Kahn at Roswell Park (now at Mayo Clinic) have both produced lines that were judged to be useful in evaluating treatments for Waldenstrom's since both cell lines exhibited the MYD88 L265P mutation. This is the third year of the cell line development project, and the IWMF is continuing support for Dr. Ansell and for Dr. Irene Ghobrial at DFCI. Dr. Ghobrial gave a preliminary report on her project to develop cell lines utilizing a mouse model at the IWMF 2012 Ed Forum. She has had success with growing mice that were injected with WM cells. In addition, Dr. Ghobrial reported the successful *in vitro* production of WM cells using growth compounds. A final report on her progress will be forthcoming this spring.

The mouse model developed by Dr. Siegfried Janz at the University of Iowa, in a research project also supported by the IWMF, does not exhibit the mutated MYD88 gene. This model may be of value in WM research as some patients do not have the mutated gene. As noted above, the newly awarded grant to Dr. Ruben Carrasco, funded jointly by the IWMF, WMFC, and LLS, is for the development of a mouse model that exhibits the mutated MYD88 gene.

The IWMF-funded project at Mayo Clinic led by Dr. Ansell shows continued progress in tracking down the proteins and transcription factors associated with the production of IgM in WM. In research completed under a previous IWMF grant, Dr. Ansell demonstrated that in WM patients the proteins BLyS and IL-6 were expressed in higher concentrations and that STAT5 was also over-expressed. His current research has studied the effect of STAT5 on the increases in BLyS and IL-6 and shown that the use of agents minimizing the performance of STAT5 also reduce the secretion of IgM. Two forms of STAT5, labeled STAT5A and STAT5B, were identified. These two proteins are encoded by separate genes but are 90% identical at the amino acid level. However, "knocking down" STAT5A in the serum appeared to be more effective in reducing IgM production than using STAT5B. This finding may open up new avenues in the treatment of WM.

The tissue bank project that Dr. Ghobrial initiated in 2010 is a major effort by IWMF to provide tissue samples and epidemiological data for researchers all over the world. The most recent report indicates that over 500 WM patients have prepared the epidemiological survey—with more than 100 completing the survey at the 2012 IWMF Ed Forum. This information, in combination with blood, bone marrow samples, and buccal (cheek) cells, can be used to identify responses to therapy and the mechanisms of resistance. It is hoped that the causes of WM and the risks of developing the cancer will become clearer as a result of this project.

Patient support of Dr. Ghobrial's tissue bank project is vital. See the October 2012 issue of the Torch, pages 3 and 31, to learn how you can register. A representative from the tissue bank project will be available at the upcoming 2013 Ed Forum in San Diego to answer questions and sign up participants.

MEET PAUL CADRIN: MUSICOLOGIST WITHOUT BORDERS

BY PETER DENARDIS, IWMF TRUSTEE

"The real art of conducting consists in transitions."— Gustav Mahler

Musicologue sans frontières: this is the tag Paul Cadrin, member of both the IWMF and Waldenstrom's Macroglobulinemia Foundation Canada, appends to his e-mails. Indeed, a quick survey of his musicological accomplishments reveals the limitless range of Paul's engagement with "the musical life"—scholar, musician, administrator. Holding a Ph.D. in theoretical musicology from the University of British Columbia, Paul found an academic home for more than 35 years was Laval University in Québec City, Canada, where he instructed in the graduate school while at the same time advancing in the University's administration from Director of Graduate Programs to Dean of the Faculty of Music. Beyond the walls of the University, Paul has played many roles over the years in the musical life of Québec including those of conductor, organist, and composer, moving freely from one role to the next.

In recognition of his versatility as both scholar and musician and his dedication to the enrichment of the cultural life of Québec, on November 27, 2012, in the Grande Théâtre de Québec, Paul Cadrin was awarded the 26th Prix de l'Orchestre Symphonique de Québec Fondation. The citation read on this occasion includes the following: "The OSQ Foundation wishes to acknowledge the work of a great scholar involved in the music world and committed to the importance of culture and the arts as driving forces of our society."

This splendid award is reason enough to offer our congratulations to Paul and to admire a life spent in traversing so many paths to fulfill his devotion to music. Our admiration, however, grows all the greater when Paul speaks candidly to us as fellow Wallies about the difficulties he faced from the time of his WM diagnosis in August of 2009 and leading up to his award in November of 2012.

This new role was that of WM patient, most likely Paul's most challenging. For a year before his diagnosis, he had been experiencing severe pain in his hips, but x-rays and bone scans revealed nothing. A follow-up PET scan, however, showed serious infiltrations of the bone marrow in the pelvis. Paul could see in the consultant's face when he read the PET scan that "this was much more serious than originally expected," and a BMB was immediately performed. The results, however, took over a week to come back from the pathologist, as those types of specialists are in short supply in Québec, and the results had to be sent to a distant laboratory. For Paul, those ten days of waiting were intense days of reflection, trepidation, and anticipation.

The results came back, and when WM was identified as the cause of the infiltrations, it was a bit perplexing to his hematologist, since WM usually does not express itself via bone pain. Paul was facing a new transition in his life, from that of a "normal" music professor, to that of a cancer warrior.

Chemotherapy treatment commenced shortly thereafter (Rituxan and cyclophosphamide) and took place every three weeks for five months, with a gradual lowering of his IgM values and a lessening of his hip pain. By a combination of sheer will and dedication, Paul was able to carry on with his professional activities "without missing a beat" throughout his chemotherapy treatments. Treatments were always on Friday; he would recuperate on the weekends and be back in class on Monday.

The pain however, came back, even though his IgM was low. A new x-ray showed a severe case of arthrosis (a degenerative disease of the joints) with necrosis in both hips, that is, a build-up of necrotic dead tissue in the hips. Apparently, the necrosis was a side effect of the chemotherapy. Surgery was required to remove the dead tissue from both hips and to replace both, each requiring a separate surgical procedure. By August 2011 the hip pain was so severe that Paul could no longer fulfill his professional duties at Laval University. At that time he took sick leave to prepare for the hip operations and then decided to retire shortly thereafter, since he was only four months away from the date that he had originally set for retirement.

The surgeries took place late in 2011, and recovery was slow. As he describes this phase of his WM journey, "I was operated on both hips, the first one on October 3, 2011, and the other one, two months later. I have now enjoyed a complete resurrection. For the past three years, I had been walking with a cane and literally counting every step I made. I am now running around without the slightest trace of pain or inconvenience from my cyber hips. And my IgMs are fully under control." We can appreciate that the award on November 27, 2012, represented a triumph of many dimensions.

Paul has conducted his transition to a life "in retirement" with great care—maintaining a good quality of life in a new setting (he has moved back to Montreal after 37 years in Québec City), and is working with a new hematologist in Montreal, who is a former assistant to Dr. Steven Treon.

Meet Paul Cadrin, cont. on page 11

Meet Paul Cadrin, cont. from page 10

These days, among many other activities, Paul can be found conducting singing workshops in two homes for elderly persons, and he enjoys that activity immensely. Helping them conduct their lives so that they can sing and move around with their canes and walkers gives him great joy as he recalls his months on end walking with the aid of canes and the peace he feels now with his ability to be back to normal. Paul is also taking time during retirement to continue his research and writing, in particular preparing the publication of a reference book on the Polish composer Karol Szymanowski.

He has proven himself to be a musicologist without borders and without barriers. He is committed to continue his efforts with music and conducting well into his retirement and well after his initial battle with WM. Through his experiences with WM and his love of music, he is able to touch and enrich the lives of others long after that first diagnosis.

"I think music in itself is healing. It's an explosive expression of humanity. It's something we are all touched by. No matter what culture we're from, everyone loves music." — Billy Joel

THE 2013 IWMF MATCHING GIFT PROGRAM IS STILL ON

If you have not already taken advantage of this opportunity to double a gift, please consider doing so now. Through the generosity of anonymous donors, we are able to match, dollar for dollar, certain **Membership Services Fund** gifts that are made between March 1 and May 15, up to a maximum of $83,000.

Gifts that are eligible for the match will come from:

- Everyone who makes a first-time gift.
- Everyone who has not made a gift in the past two years.
- Everyone who increases their 2013 Member Services giving from March 1st until May 15th over their 2012 Member Services giving from March 1st until May 15th-—the amount increased will be matched.

And all Tribute and Memorial gifts will be matched.

Won't you make your next gift count double?

Medical News Roundup, cont. from page 8

peripheral neuropathy. KRN5500 is an IV-administered, non-opioid pain reliever with rapid onset of action and prolonged pain relief. The drug successfully completed a Phase IIa trial. Orphan Drug Designation qualifies DARA Biosciences for tax credits and market exclusivity during drug development.

Oral Proteasome Inhibitor in Phase I/II Clinical Trial – Preliminary findings from a Phase I/II multicenter study of a new proteasome inhibitor called MLN9708 were reported at the 2012 ASH conference by the Mayo Clinic in Rochester, MN. This study of 53 newly diagnosed multiple myeloma patients combined MLN9708 with lenalidomide (Revlimid) and dexamethasone. MLN9708 is the first oral proteasome inhibitor to enter clinical trials, and the recommended dosage is 4 mg once weekly. The overall response rate in this study was 90%, and responses were durable for up to 13.2 months. The study investigators reported that MLN9708 has a favorable toxicity profile with low rates of peripheral neuropathy. MLN9708 is also being investigated for the treatment of relapsed/refractory systemic light-chain amyloidosis.

Anti-CD38 Monoclonal Antibody Studied in Multiple Myeloma – An anti-CD38 monoclonal antibody called daratumumab is in an ongoing Phase I/II trial for 32 previously treated multiple myeloma patients. Preliminary results reported by Dr. Torben Plesner from Vejle Hospital in Denmark indicate promising activity as a single agent treatment, with reductions in both bone marrow plasma cells (80-100%) and in monoclonal protein (33-100%) at a dosage of 4 mg/kg or greater. The most common toxicities reported were infusion-related reactions, and the trial researchers have since implemented a steroid regimen prior to all infusions to reduce the number and severity of these reactions.

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

ASH 2012 HIGHLIGHTS

By Sue Herms, IWMF Trustee

The 54th Annual Meeting of the American Society of Hematology (ASH) was held on December 8-11, 2012, in Atlanta, GA. The IWMF staffs a booth each year at this conference, which attracts hundreds of clinicians and researchers, as well as exhibitors from pharmaceutical companies, medical technology industries, and patient advocacy groups. The IWMF was represented by Dr. Robert Kyle, Trustee and Chair of the Scientific Advisory Committee (SAC); President Carl Harrington; Vice President for Research Tom Myers; and Business Office Manager Sara McKinnie.

A number of poster and oral presentations at ASH focused on WM, and they are organized here into broad topics. Some interesting trends were noted in this year's ASH abstracts. One was the number of studies assessing the prevalence of and attempting to characterize the importance of the MYD88 L265P mutation in WM cells. Another trend was the number of abstracts discussing how and why IgM-MGUS can progress to WM, and a third involved several analyses of how the WM clone changes over the course of disease progression.

BIOLOGY OF WM

Dr. Guang Yang, et al. from Dana-Farber Cancer Institute sought to identify the pathway(s) by which the MYD88 L265P mutation promotes the growth and survival of WM cells. This mutation was identified as being widely expressed (>90%) in WM patients in recent studies reported by Dr. Steven Treon at the same institution. WM cells were isolated from bone marrow biopsy specimens of WM patients in a series of experiments that identified activation of Bruton's tyrosine kinase (BTK) by the mutation as an important factor that promotes the survival of WM cells. BTK is an enzyme that plays a crucial role in B-cell development and mast cell activation. The use of a BTK inhibitor (PCI-32765) blocked NF-kappa B and STAT3 signaling, induced WM tumor cell killing, and was enhanced by the presence of an IRAK1/4 kinase inhibitor.

Dr. Anne J. Novak, et al. from the Mayo Clinic sought to confirm the incidence of the MYD88 L265P mutation in this institution's WM/LPL and other indolent lymphoma patients and to identify the cell pathways that it impacts. MYD88 plays a key role in the immune response and activates a cell signaling cascade that results in activation of NF-kappa B and STAT3 signaling. This study found that 70% of WM tumors had the mutation and that a validation set of WM patients had a similar mutation rate of 68%. Additionally both the MWCL1 and the BCWM.1 cell lines, which are used in pre-clinical studies of WM, display the mutation. Using these cell lines, the researchers wanted to confirm that the L265P mutation can activate the MYD88 pathway, and their data suggest that such is indeed the case, resulting in activation of NF-kappa B. Next, they wanted to confirm the significance of the MYD88 pathway on lymphoma cell growth. Again using the cell lines, they tested the effect of IRAK1/4, TAK1, and NF-kappa B inhibitors on cell growth and found that the cell lines were sensitive to the TAK1 and NF-kappa B inhibitors in a dose dependent manner; however, sensitivity to the IRAK1/4 inhibitor was detected only at the highest dose in one cell line. Additionally, the same inhibitors reduced the level of Interleukin 10 (IL-10) secreted by each of the cell lines. IL-10 is a cytokine (cell signaling protein) that enhances B-cell survival, proliferation, and antibody production.

Angiogenesis (new blood vessel formation) is elevated in many blood cancers, but there is limited information about angiogenesis in WM. To address this issue, an abstract presented by **Efstathios Kastritis,** et al. from the University of Athens in Greece reported on the serum levels in WM patients of several cytokines (cell signaling proteins) that influence angiogenesis, including VEGF, VEGF-A, bFGF, angiogenin, Ang-1, and Ang-2. Serum was drawn from 55 untreated patients with symptomatic WM, 12 patients with IgM-MGUS, and 30 healthy controls. All serum levels of these cytokines except Ang-1 were markedly increased in WM patients compared to controls, and these levels correlated with serum beta2-microglobulin levels and with staging according to the International Prognostic Scoring System for WM. The levels of Ang-2 increased as the disease evolved from IgM-MGUS to symptomatic WM, while the levels of Ang-1 decreased. The researchers suggest that the levels of Ang-2 may be associated with significantly shorter progression free survival.

Dr. Yang Cao, et al. of Dana-Farber Cancer Institute discussed the use of whole genome sequencing (which determines the complete DNA sequence of an individual) to identify a mutation in the CXCR4 gene which is present in 29% of WM patients. The gene plays an important role in the development of lymphocytes and their movement in and out of the bone marrow. Mutations in this gene can lead to increased movement of cells, and the study suggests that CXCR4 inhibitors might be useful in the therapy of WM.

Dr. Lucy S. Hodge, et al. from the Mayo Clinic examined the role of T-cells in the tumor environment and their influence in the biology of malignant cells of many blood cancers, often through cytokine (cell signaling protein) interactions. Recent studies involving healthy B-cells and CD4 T-cells identified interplay between the Interleukins IL-6 and IL-21, whereby IL-6 increased IL-21 production by T-cells, driving the differentiation and IL-6 secretion of nearby B-cells. In WM, IL-6 is elevated in the bone marrow and is associated with increased IgM production. However, the function of IL-21 in WM and its relationship to IL-6 is poorly understood.

ASH Highlights, cont. on page 13

ASH Highlights, cont. from page 12

In this study, special stains for cell surface markers revealed significant IL-21 staining associated with T-cells in the bone marrow of patients with WM. Additional work indicates that this T-cell-derived IL-21 significantly promotes growth and immunoglobulin production by malignant B-cells.

In another abstract, **Dr. Hodge** reported on the biologic activity of STAT5A and STAT5B in WM. The STAT proteins are messengers that influence responses to various cytokines (cell signaling proteins). Abnormal activity of STAT5 has been implicated in the development of blood cancers due to its ability to regulate genes involved in cell growth and survival. Several bone marrow studies indicated higher expression of STAT5 in WM patients compared to normal controls. Several WM cell lines were treated with an inhibitor of STAT5 and showed significantly decreased IgM secretion; effects on growth and viability of cells were also observed. Inhibition of STAT5A in particular resulted in diminished IL-6 and IgM secretion. Further characterization of STAT5 is ongoing in order to understand the specific roles of STAT5A and STAT5B in WM tumors.

Dr. Wendy Beguelin, et al. from Weill Cornell Medical Center and Columbia University looked at B-cell cancers with plasma cell-like differentiation, including WM/LPL and marginal zone lymphoma, to see if they could find some common disease-causing mechanism. The researchers observed that Interleukin 10 Receptor a (IL10RA) was abnormally over-expressed due to epigenetic hypomethylation, which is a chemical alteration of gene expression. This may promote survival and expansion of lymphoma cells; consequently two anti-IL10RA antibodies were tested on cell lines, including LPL. Both antibodies markedly inhibited growth via signaling through JAK/STAT and MAPK cell pathways and could be explored as potential therapy for WM.

DIFFERENTIAL DIAGNOSIS

Based on Dr. Steven Treon's discovery of the highly recurrent L265P mutation in the MYD88 gene of WM patients, **Luca Arcaini,** et al. of Italy assessed the prevalence of this same mutation in 271 patients with several types of B-cell disorders, including WM, IgM-MGUS, and splenic marginal zone lymphoma. DNA was obtained from both bone marrow cells and peripheral blood, and the presence of the mutation was assessed by a PCR (polymerase chain reaction) test method, which amplifies the DNA in a sample so that it can be more easily detected. The L265P mutation was detected in 100% of the 58 WM patients tested and in 47% of the 77 patients with IgM-MGUS. In addition, it was detected in 6% of 84 splenic marginal zone lymphoma patients and in 6% of 52 patients with other chronic B-cell proliferative disorders. The researchers concluded that the presence of the L265P mutation could be a useful diagnostic tool for WM and IgM-MGUS. They also noted that, compared to IgM-MGUS patients without the mutation, IgM-MGUS patients with the mutation had higher levels of IgM, lower levels of IgG, a higher incidence of Bence-Jones protein in their urine, and a greater risk of disease progression.

A French study by **Stephanie Poulain,** et al. also studied the incidence of the L265P mutation in 67 untreated WM patients, along with 9 chronic lymphocytic leukemia (CLL), 4 multiple myeloma (MM), and 9 marginal zone lymphoma patients. The French group observed the mutation in 79% of WM patients, and an alteration in the copy number of the unmutated MYD88 gene in an additional 6%. No difference in terms of survival was observed according to the MYD88 mutation status. No MYD88 L265P mutation was observed in CLL and MM, while one marginal zone lymphoma patient had the mutation.

DISEASE PROGRESSION

A French study by **Dr. Xavier Leleu,** et al. discussed a possible mechanism for understanding how and why indolent or smoldering (asymptomatic) WM progresses to symptomatic disease requiring treatment. Seventeen patients, 8 smoldering and 9 symptomatic, were included in this study, which selected tumor cells from the bone marrows of these patients for gene expression profiling. Dr. Leleu's group discovered that two important pathways appeared to distinguish between these two types of patients: the plasma cell differentiation pathway and the AKT pathway. In particular, the researchers identified three key genes in these pathways – BACH2 and CIITA in the plasma cell differentiation pathway and PTEN in the AKT pathway – that were over-expressed in the smoldering patients compared to the symptomatic patients. BACH2 is known to be a tumor suppressor gene that reduces proliferation and induces cell death when present in B-cell lymphoma cells. Interestingly, the BACH2 gene is located on chromosome 6q, the deletion of which is the most frequently reported chromosomal abnormality in WM. Thus, it appears possible that a loss of BACH2 expression could lead to the development of symptomatic WM from smoldering WM and that this gene may be a candidate to better understand the underlying mechanisms of progression of WM.

An Italian study, reported by **Dr. Alessandra Tedeschi,** et al. identified gene expression profiling patterns of WM and IgM-MGUS. CD19+ and CD138+ bone marrow cells were isolated from patients in both groups. Several genes involved in the regulation of transcription (the process whereby genetic information is copied from DNA to RNA) were significantly over-expressed in WM CD19+ cells vs. IgM-MGUS CD19+ cells. Also, several genes were involved in the AKT and MAPK cell signaling pathways, which can play an important role in WM cells in the regulation of several biological processes including cell growth, differentiation, survival, migration, and metabolism. Another set of over-expressed genes in WM 138+ cells, compared to those of IgM-MGUS, are involved in B-cell activation and the immune response. These differences could clarify the processes underlying

ASH Highlights, cont. on page 14

IgM-MGUS and WM and could help identify IgM-MGUS patients who are at high risk for progression to WM.

Another Italian study performed extensive flow cytometry (cell surface marker) analysis for identification of the WM clone in IgM-MGUS and WM. **Bruno Paiva,** et al. analyzed bone marrow samples from 244 patients, including 67 IgM-MGUS, 77 smoldering, and 100 symptomatic newly diagnosed WM patients. The study first analyzed the percentage of B-cells and plasma cells and then the percentage of light chain restricted cells in both sets of cells. Light chain restriction can identify the presence of clonal cells by determining if they are all either kappa or lambda type. The results showed a progressive increase in B-cells from IgM-MGUS to smoldering to symptomatic WM (2%, 9%, and 12%, respectively), as well as an increase in light chain restricted B-cells (75%, 96%, and 99%, respectively). In contrast, the percentage of plasma cells did not increase from IgM-MGUS to smoldering to symptomatic WM, but the percentage of light chain restricted plasma cells did (70%, 85%, and 97%, respectively). The study determined that an increased number of B-cells and light chain restricted B-cells, but not plasma cells, tended to predict an increased risk of progression from smoldering to symptomatic WM and inferior overall survival in symptomatic WM. There was also a progressive increase in CD22, CD25, and sIgM markers in B-cells from IgM-MGUS to smoldering to symptomatic WM. A bimodal expression of the B-cell memory marker CD27 (from negative to positive) was found in more than 50% of WM patients, raising the possibility that the WM clone may arise, at least in some cases, before antigenic stimulation; subsequent development of the clone into plasma cells would explain the presence of somatic hypermutations (the process whereby B-cells acquire additional mutations to better target antigens). B-cells from IgM-MGUS and WM patients were negative in 90% of cases for surface markers CD5, CD10, CD11c, and CD103, which can be useful for differentiating between WM and other B-cell non-Hodgkin's lymphomas. Within the plasma cell compartment, there was a progressive increase of light chain restricted clonal plasma cells displaying an immature appearance, as patients progressed from IgM-MGUS to smoldering to symptomatic WM.

Stephanie Poulain, et al. from France discussed the evolution of the WM clone during the course of disease. Current models of cancer progression suggest that cancer cells acquire additional genetic lesions over time because they are inherently genetically unstable. This particular analysis looked at changes in clonal WM bone marrow cells of 19 untreated individuals compared to paired normal cells in the same patients. At initial sampling, the analysis detected a total of 76 alterations in the normal number of gene copies, including 22 gains and 54 losses; 85% of patients had the MYD88 L265P mutation. During follow-up of WM patients who remained indolent, no new genetic abnormalities have been observed. Among the 11 remaining patients, genetic changes were observed in 6 cases. The early data support the hypothesis that symptomatic disease favors genetic clonal evolution of tumor cells.

FAMILIAL WM

A joint Duke University-National Cancer Institute study, reported by **Dr. Mark C. Lanasa,** et al. examined the prevalence of circulating malignant B-cells in IgM-MGUS and WM/LPL by using flow cytometry (cell surface marker detection). This work is based on previous studies which showed that clonal populations of chronic lymphocytic leukemia (CLL)-like circulating B-cells can be identified in 18% of family members of CLL patients. Because CLL and WM/LPL have related gene expression profiles and shared genetic risk, this study hypothesized that unaffected family members of WM/LPL families would also have detectable circulating clonal B-cell populations. A total of 155 individuals were analyzed. Twenty of 41 WM/LPL patients (49%) had peripherally circulating B-cell clones detected. Interestingly, peripherally circulating B-cell clones were detected in 9 of 17 cases (53%) of IgM-MGUS, a proportion nearly identical to that identified in WM/LPL. Among unaffected family members, however, the study identified circulating B-cell clones in only 4 of 81 (5%), and these more closely resembled CLL-like clones. Unlike the CLL-like clones, most of the clones identified in WM/LPL patients have an otherwise normal B-cell phenotype and can only be detected by the presence of light chain restriction – that is, the cells all have one type of light chain, either kappa or lambda, indicating clonality. This likely limits the ability of flow cytometry to detect low levels of WM/LPL clonal cells in the bloodstream.

PRE-CLINICAL DRUGS

Dr. Isere Kuiatse, et al. discussed pre-clinical results in a multi-center study of a spleen tyrosine kinase (SYK) inhibitor called fostamatinib in cell lines and animal models of WM. SYK is over-expressed in WM cells, and a recent Phase I/II trial of fostamatinib in patients with a variety of non-Hodgkin's lymphomas showed evidence of activity in three patients with WM. In this multi-center study, fostamatinib reduced the viability of WM cell lines and delayed tumor growth in mice which were injected with cells from a WM cell line.

Ublituximab is a novel chimeric (part mouse/part human) anti-CD20 monoclonal antibody that has been engineered with a high affinity for the FcyRIIIa receptor, which is involved in the success of response to rituximab therapy. A French study, reported by **Magali Le Garff-Tavernier** of Pitié Salpêtrière, evaluated this new antibody's ability to activate natural killer cells and compared it to rituximab. Natural killer cells are an important part of the body's immune system that target B-cells attached to rituximab (and other anti-CD20 antibodies) and kill them. Blood samples from 37 untreated WM patients and

ASH Highlights, cont. on page 15

from 30 age-matched healthy patients were collected. At low concentrations, a significantly greater amount of natural killer cell activation was observed with ublituximab, regardless of patient group. A phase I/II trial with single agent ublituximab in patients with rituximab relapsed/refractory non-Hodgkin's lymphoma, including WM patients, is now underway.

CLINICAL TRIALS

Preliminary results from a Phase I dose-escalation study of MLN0128 (INK128) were reported by **Dr. Irene Ghobrial,** et al. in a multi-center study. This drug is an oral inhibitor of the mTOR complexes 1 and 2 (TORC1/2). The study included relapsed/refractory multiple myeloma, non-Hodgkin's lymphoma, and WM patients, who received the drug either daily or for 3 days on and 4 days off each week, in 28-day cycles. The dose was escalated based on toxicities exhibited in cycle 1. The maximum daily tolerated dose was determined as 6 mg, while the maximum tolerated dose for the 3 day-per-week schedule has not yet been defined. Overall, 89% of patients had a drug-related event, including nausea, fatigue, hyperglycemia (high blood sugar), thrombocytopenia (decreased platelets), mucosal inflammation, vomiting, and anemia; 57% of patients had dose reductions/modifications and 27% discontinued treatment. Among 27 patients evaluated for responses, most were MM patients – two of the three WM patients enrolled had stable disease at this preliminary point.

Dr. Meletios Dimopoulos, et al. from the Greek Myeloma Study Group produced a final analysis of a Phase II study of dexamethasone, rituximab, and cyclophosphamide (DRC) for the primary treatment of WM. Between November 2002 and April 2006, 72 WM patients were enrolled in this trial, which consisted of dexamethasone IV and rituximab IV on day 1 and oral cyclophosphamide on days 1-5. DRC courses were repeated every 21 days for six courses, and then patients without progressive disease were observed without further treatment. Eighty three percent of patients achieved a response, including 7% complete, 67% partial, and 9% minor responses. The study was updated in June 2012 to assess time to progression, time to next treatment, type and response of second-line treatment, overall survival, and cause-specific survival. Second line treatment was administered to patients who experienced progressive disease and met criteria for re-treatment. The median time to progression was 35 months, and the median time to next treatment was 51 months. Among several factors analyzed for correlation with shorter time to progression, only lymphadenopathy (enlarged lymph nodes) was significant. Among 40 patients who received second-line treatment, 28 were re-treated with either rituximab alone, with DRC, or with rituximab combined with other agents; the remaining 12 patients were treated with alkylating agents, nucleoside analogues, bortezomib, or high-dose (autologous stem cell transplant) therapy. So far, 35 patients (49%) have died, including 15 patients from unrelated causes. One patient who received therapy with fludarabine developed myelodysplastic syndrome, which is ineffective production of the myeloid blood cells; two patients developed diffuse large B-cell lymphoma (one after DRC and one after multiple treatments including alkylating agents and fludarabine). The median overall survival and cause-specific survival were 95 months and 104 months, respectively. So far, DRC has not been associated with development of secondary myelodysplasia.

Dr. Mathias J. Rummel, et al. reported on a multi-center study in Germany and Austria of bendamustine and rituximab (BR) therapy for newly diagnosed WM patients, followed by either observation or by rituximab maintenance. Treatment consisted of a maximum of six cycles of BR administered every 28 days plus two cycles of rituximab every four weeks. Responding patients were randomized to observation or to two years of rituximab maintenance every two months. At this time, 116 of 162 WM patients were evaluable for response; the overall response rate to the initial therapy was 86%. Also, 43 patients are being observed and 47 patients are receiving rituximab maintenance therapy, but results are not yet available to report from this part of the trial. No uncommon toxicities were observed during initial therapy.

A multi-center Phase I trial of bortezomib (Velcade) and alvocidib (flavopiridol) was reported by **Dr. Beata Holkova,** et al. The study enrolled 43 patients with multiple myeloma and non-Hodgkin's lymphoma (including 2 WM patients) with recurrent or refractory disease. This trial was based on pre-clinical studies suggesting that cancer cells may be particularly sensitive to simultaneous interruption of cell cycle and survival signaling pathways. Alvocidib is a cyclin-dependent kinase inhibitor that interacts with bortezomib, and the primary objective of this trial was to identify the maximum tolerated dose for this treatment combination. Both drugs were given as intravenous infusions. Toxicities included dehydration, diarrhea, fatigue, anemia, loss of appetite, neutropenia (decreased neutrophils), lymphopenia (decreased lymphocytes), peripheral neuropathy, and thrombocytopenia (decreased platelets). Of the 43 patients treated, 38 have been evaluable for response; response rates were 33% for non-Hodgkin's lymphoma and 35% for multiple myeloma. Patients are still being enrolled, and the maximum tolerated dose has not yet been reached.

Dr. Anna Guidetti, et al. treated relapsed/refractory lymphoma patients with a combination of the oral AKT inhibitor perifosine with the oral multikinase inhibitor sorafenib. This Phase II Italian clinical trial enrolled 40 heavily pretreated patients (including one WM patient) and started with a 4-week treatment of perifosine alone to assess tolerability and tumor response. Patients achieving less than a partial response were given the combination therapy until disease progression or significant toxicity. The most common toxicities were anemia, thrombocytopenia (decreased platelets), diarrhea, and joint pain. The results

ASH Highlights, cont. on page 16

of the combination therapy included 22% of patients with a partial response and 42% with stable disease. After a median follow-up of 14 months, the median overall survival and progression free survival were 16 and 5 months, respectively. The most promising responses were seen in patients with Hodgkin's lymphoma.

OTHER ABSTRACTS OF INTEREST

A multi-center international study presented by **Dr. Malin L. Hultcrantz,** et al. noted that most plasma cell malignancies are associated with an elevated risk of thromboembolism. This is the formation of a blood clot that breaks loose and is carried by the bloodstream to plug another blood vessel. There is limited information on the frequency of venous and arterial thrombosis in patients with WM. Patients diagnosed with WM/LPL between 1986 and 2005 were identified through various Swedish registries and were matched with normal controls. Venous thrombosis was defined as pulmonary or deep vein thrombosis, and arterial thrombosis was defined as myocardial infarction (heart attack), angina pectoris (chest pain due to coronary artery disease), cerebral infarction (stroke due to blood clot), or transient ischemic attack (brief loss of blood flow to the brain). Patients with WM/LPL had a two to four fold elevated risk of venous thrombosis compared to controls, possibly due to their hypercoagulable state (increased tendency to clot), co-morbidities, decreased mobility, and treatment-related factors. Interestingly, although an elevated risk of arterial thrombosis has been identified in multiple myeloma, IgG-MGUS, and IgA-MGUS, there was not an elevated risk in WM or IgM-MGUS patients. These results suggest that, even though WM is associated with hyperviscosity due to the size and shape of the IgM molecule, the risk of arterial thrombosis is not increased. This may also indicate that IgM-associated disorders do not share the same thrombotic mechanisms as IgG and IgA plasma cell disorders.

Dr. Sheeba K. Thomas, et al. from MD Anderson Cancer Center evaluated the impact of rituximab on overall survival of WM patients. This study retrospectively examined patients treated at this center with combinations of alkylating agents, nucleoside analogues, or bortezomib, each with or without rituximab. The effect of primary therapy was compared between patients receiving treatment before and after rituximab use for WM began at this institution in 1998. Among 315 patients treated since 1966, median overall survival with rituximab was more than 13 years vs. 5.6 years for those treated without rituximab, a significant improvement.

Dilshad Khan, et al. from MD Anderson Cancer Center performed a retrospective review of 55 patients with WM who underwent stem cell collection at this institution, either through peripheral blood (PB) collection (53 patients) or bone marrow harvest (2 patients). The 53 patients who underwent peripheral PB collection were mobilized with either growth factors only (34) or with growth factors plus chemotherapy (19). Of the 53 PB patients, two failed to mobilize stem cells and two had inadequate collection. Fifteen patients had received cladribine therapy prior to collection, and 14 of them had adequate stem cell harvests; however, 7 of the 15 required growth factors plus chemotherapy in contrast to 11 of 39 who did not have prior cladribine therapy. Of those patients with adequate stem cell collection, 34 banked their stem cells for use at time of relapse, and 17 proceeded almost immediately to autologous transplant. Forty four of the total 51 patients (PB and bone marrow harvest) who collected successfully are alive after a median of 37.5 months. Current frontline regimens for WM are associated with high overall response rates, but complete responses are low. Given the feasibility of stem cell collection, the researchers suggest that incorporation of autologous stem cell transplant for younger patients could be studied as a means of improving complete response rates, perhaps also improving both remission duration and overall survival.

If you have questions about ASH 2012 or would like to have an electronic file of ASH 2012 abstracts on WM, please contact the author at suenchas@bellsouth.net.

HOW TO JOIN IWMF-TALK

Here are two ways to join:

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   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*
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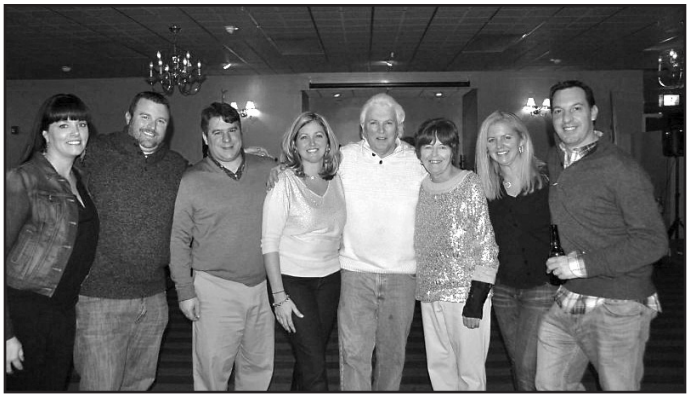
MEMBER STORIES: UNIQUE WAYS TO FUNDRAISE

BY JULIE JAKICIC, FUNDRAISING TEAM



The O'Soro family at this year's party: from l to r, Jessica & Mike O'Soro, Greg & Jen Afarian, Charles & Nancy O'Soro, Lisa & Steve Lawton.

There are many ways you can help the IWMF raise funds without stretching your wallet any further. Have you thought about asking your friends, family members, or colleagues to donate in your honor when celebrating a birthday or event? Have you considered holding a fundraiser? Over the past six months a number of our members used different approaches with much success. The following are some examples.

When **Edward Goldberg** was diagnosed with WM, his colleagues asked what they could do to help. Edward asked them to donate to the IWMF, and they enthusiastically responded. Then he took it one step further. As a benefit to his medical staff during his professional career as the CEO of a large hospital, Edward would coach staff children who were applying to medical school, dental school, veterinarian school, or nursing school by reviewing their personal statements and coaching their interview techniques. Edward retired in November 2012. He continues to coach children of the hospital employees, but he now charges a fee and asks that it be sent to the IWMF. To date his program has raised $3,625.

A personal approach can be very effective. **Judy** and **Mal Roseman,** for example, have donated to charities on behalf of friends and family members for years, without ever asking for donations in support of their charity of choice, the IWMF. A friend finally inquired when they were going to ask him to support their charity. Mal and Judy thought about it, and, as Mal explains, "We initially felt awkward, asking friends, neighbors, and family members for money, but our friends encouraged us." So they crafted an e-mail, sent it out, sat back, and waited. Everyone responded enthusiastically! Several friends increased the value of their contributions through matching gift programs at their place of employment. That well-crafted e-mail even inspired one friend to become further involved. Now he is lining up prizes so that he can hold his own raffle next year in order to raise funds in honor of Judy!

Marcia and **Ken Wierda** raise money for the IWMF in several ways. Marcia asked friends and family to donate to the IWMF in honor of her recent birthday. Ken's employees surprised him with an office collection sent to the IWMF in his name. Marcia and Ken also have a vacation condo that they rent to friends and family, and the rent is directed to the IWMF. When **Carl Harrington** was elected as IWMF's President, his wife **Elly** sent a letter to their friends and family, asking if they would honor this momentous occasion by sending a donation to the IWMF in Carl's honor. Thirty-five people responded to Elly's request! The IWMF received further donations when **Martin Edelman** turned 80 (congratulations, Martin!) this year and asked his friends and family to send donations to the IWMF instead of giving him gifts. And family and friends joined **Norman** and **Sharon Poteshman** in celebrating their Fiftieth Wedding Anniversary by sending donations to the IWMF in lieu of gifts.

Collectively, the Rosemans, the Wierdas, the Harringtons, the Poteshmans, and Martin Edelman have raised $33,645 by their personal appeals!

The O'Soro family has turned fundraising for the IWMF into an annual event, a festive party that the guests look forward to every year. When **Nancy O'Soro** was diagnosed with WM, her three children wanted to find a way to increase recognition of this orphan disease this orphan disease as well as to raise funds. And so the O'Soro Family Fundraiser was born. Now the whole family pitches in to create a night to remember. Every January the O'Soro family and friends rent a hall and find a DJ or band to play pro bono. Fliers are sent in advance to friends, family, and colleagues, and tickets are also sold in advance. Many people bring food and raffle prizes. Apart from the hall rental, there is no other overhead cost. The raffle is typically the hit of the party. Nancy's husband **Charles** donated an iPad mini this year; other items included a Starbucks Verismo coffee maker, wine baskets, tailgating baskets, gift cards to local restaurants, Bruins tickets, and more. All the proceeds from ticket sales go directly to the IWMF. As **Lisa Lawton,** Nancy's daughter, describes the O'Soro event, "I have people telling me in October how excited they are for the fundraiser coming up in January. It's a really nice way to recognize my mother and her illness as well as visit with family and friends and have a night of socializing and dancing." This year was the tenth year for the O'Soro Family Fundraiser! Over the course of ten years they've raised $47,755 for the IWMF!

In the past we've received donations from small business owners who donate a portion of their sales. We've received contributions through members running in marathons and riding in bike races. You can do the same by holding a fundraiser or by asking your friends, family members, and colleagues to donate in your honor for an upcoming celebratory event or just because! Be creative! Make it fun! As the IWMF members mentioned above have proven, it can be as simple as asking.

A SELF-CARE APPROACH TO LIVING WELL WITH WALDENSTRÖM MACROGLOBULINEMIA

BY WANDA HUSKINS, IWMF MEMBER

"The oldest and strongest emotion of mankind is fear, and the oldest and strongest kind of fear is fear of the unknown."—H.P. Lovecraft

I am driving at night along a dark, unfamiliar highway. I can't see ahead of me. What I mean is that I see only a dark void. My visual field extends and abruptly ends immediately in front of me. Despite the impossibility of continuing this way, I seem powerless to pull over and stop the car. Flashing before me are road hazards beyond my control to avoid. I strain to see. I gasp in anticipation of crashing. I veer left and right hoping to escape sudden obstacles in my path. As I struggle to concentrate my focus on what is up ahead, I'm invariably wondering, "Why is this happening? How is it that I've found myself in this surreal situation?" I scream out in anguish to my husband who is sitting helplessly next to me, "Jeff, I can't see anything ahead!" I'm terrified, confused, and exhausted, as I plead for him to help guide me.

At this point I abruptly wake up in a sweat, relieved that this is just a nightmare. Soon I begin to realize the dream's significance. My life had abruptly become unrecognizable since my Waldenström macroglobulinemia diagnosis. Now most of my waking thoughts revolved around the significance this diagnosis had and would yet have in my life. Like the road hazards springing up in my dream, our calendar was looking quite hazardous and chaotic with a sobering array of upcoming cancer-related appointments. I feared their arrival and braced myself for the worst. More frightening still was what did not show up on my cancer calendar. As in the dream, I was finding it challenging, if not impossible, to proceed without seeing what was ahead. My formerly ordinary and rather predictable life was slipping away from me. Plunged into this uncertainty I thought of a quote from Winston Churchill: *"If you're going through hell, keep going."* After four years of going through WM, three of which involved treatments, I've learned that you do have to keep going.

Sir Winston humorously presented the problem and the solution but was less forthcoming about the tools needed to manage this march through the dark unknown. The darkness ahead feels strange and menacing. It is certainly unpredictable, creating for many fear and distress in their everyday lives. No matter where we find ourselves in the cancer continuum, we're keenly aware that there is nothing normal about living with cancer, particularly a chronic cancer that has set up a permanent residence in our bodies. Life with cancer as opposed to living after cancer will be a different experience for us: *"What lies behind us and what lies before us are tiny matters compared to what lies within us."*—Ralph Waldo Emerson

In varying degrees, all of us have strengths to effectively cope with the changes and fears brought on by our cancer. Our personality traits in large measure will play the pivotal role. Some traits, including openness and a generally positive outlook on life, will clearly enhance effective coping. The "laid back" attitude of taking and living one day at a time is a strong asset to possess in dealing with uncertainty. Also key is a flexible nature with the ability to allow for adjusting plans or strategies as needed while staying committed to a goal. Of course, a high tolerance for stress, often coming from past experience in handling life's challenges, bolsters one's resolve. An important attribute to encourage positive coping skills is a strong belief system that, be it spiritual or philosophical in nature, ultimately leads to reflection and understanding of our highest priorities. Also of huge importance is the ability to ask for or accept help from others without feeling that this is a weakness. In this list of traits we can't neglect intelligence, insight, and a sense of curiosity for information and knowledge to help guide us. Researchers are also discovering the importance of humor, albeit at times "black humor," as a personality trait offering a deflection from our fears.

Most of us will find our cancer and its treatments to be challenging even if we possess some, or even all, of the traits outlined above. We arrive at this diagnosis as adults with our personalities firmly developed into our identity, and we are not readily amenable to change. The good news, however, is that our behaviors, habits and reactions are often learned responses within our control to alter. We are all quite capable of acquiring new coping skills, augmenting the ones we have, and assisting with the improvement of our own well-being. The only requirements are the desire and insight to find what our own "self-care" should look like. Devising a self-mediated care plan places us in a better position to directly manage our fears and uncertainty.

To become and to stay informed about our own cancer reduces some of that uncertainty and can improve our day-

A Self-Care Approach, cont. on page 19

to-day problem solving and can empower us to take part in our treatments. Some of us may feel the need, and have the intellectual aptitude, to delve deeply into the "science" of this disease while others may feel more confident by going slowly and selectively through the information available. No one will be grading you on your knowledge of WM! So, whatever your personal learning style is, accept it and be comfortable with it.

The care you take of your physical health is the foundation for self-care. Concern for your health should begin even before a disease strikes, and it becomes vital after diagnosis. Maintaining optimal health will afford us the best opportunity to live many quality years with WM. Optimal health is maintained by proper nutrition, exercise as tolerated, and adequate rest and sleep. But self-directed care is much more than just maintaining a healthy body. It also includes our mental health and well-being. Often one will influence the other, so maintaining or improving the health of body and mind will smooth the path we are traveling.

Exercise, or movement therapy, is the perfect example of the interplay of mind and body. The Mayo Clinic has recently completed a study on the effects of exercise on the cancer patient while undergoing treatment and published the results in the *Journal of Pain and Symptom Management.* The program is called Rapid Easy Strength Training, or REST for short *(mayoclinic.org/news2012-rst/7202.html).* It is a walking program combined with a series of gentle resistance movement exercises. Patients in the test reported less fatigue, more energy, better quality of life, improvement in mood and self esteem, less nausea, a sense of control, better sleep, decreased anger, and increased cognition. Overall, patients in this exercise study stayed physically healthier, with muscle mass maintained or improved. Other research has shown that endorphins rise with exercise while cortisol levels drop— effects that can offer a quick mood response. Clearly, exercise helps the mind and body in a lasting way.

A diagnosis of cancer produces a more introspective period in our lives when we contemplate our very existence. We may focus on spirituality or for a philosophical understanding of our life. Often people who have been diagnosed with cancer find gratitude for what they do have. Others may feel compelled to donate or contribute in some way to a particular cause. Some strikingly new insights may emerge to offer clarity about what is important to us and what is not. The resulting insights have even been called the "gift" of cancer. In any case our most complex and creative ideas may emerge from the deep dark thoughts that are associated with sad, reflective mood states. Sadness itself can be a healing tool, as it acts like a launch pad to creative thinking that can lift despair. We can even use our anger and frustration to our benefit by identifying their source and managing them constructively. Even tears, oddly enough, can be therapeutic. A "good cry" creates a hormonal release of cortisol and a sense of calm afterwards.

For some, this introspective time can lead to a desire to express feelings and emotions in writing, art, or music. In fact, the creative arts are so therapeutic that all are encouraged to "express themselves." No particular talent is required. The poet (and monk) Thomas Merton once said, "Art enables us to find ourselves and lose ourselves at the same time." Writing or keeping a journal may help us chart a direction forward and clarify the goals we want to obtain. At Georgetown University's Lombardi Comprehensive Cancer Center, recent research on this subject was conducted with leukemia and lymphoma patients. It was found that writing sessions, even in the waiting room, helped to improve the outlook of patients regarding their cancer and treatment. Listening to music or playing an instrument can also be therapeutic for the soothing effects on a worried mind. Even without knowing how to play an instrument, we can respond favorably to the listening experience. One need only observe the number of patients receiving chemo with earphones on, listening to their preferred music. The sound is familiar and comforting over the extraneous noise in the chemo suite. The expressive arts offer a way to safely face our concerns without judgment from others, while we benefit from increased self-awareness and purging negative thoughts.

The decisions we need to make require a calm and focused mind. Taking a step back in order to distance ourselves from the emotional impact may be required. Recent research has shown a range of mind-body methods that can actually shift frontal brain activity toward a new pattern of more positive and goal-oriented thinking in many people. Popular among them is meditation, which helps to decrease troubling thoughts by enhancing our internal attention toward the here and now. Relaxation exercises, along with deep breathing techniques, guided imagery, reflexology, aromatherapy, therapeutic massage, acupuncture, and even self-hypnosis can help promote a relaxed state of mind. Some cancer centers now include such teaching programs. Yoga, which means 'union' in Sanskrit, is a favorite program offered at these centers. Yoga promotes tranquility of the mind by inducing a

A Self-Care Approach, cont. on page 20

relaxation response. Many find it quite restorative. You may still be aware of your fears, but you are diffusing them by turning down their volume. Ultimately, any of these methods should reduce worry and anxiety and offer better emotional stability, concentration, and mindfulness. Remember, the mind also needs to rest from the stress of cancer.

Mindfulness is a term that relates to internal awareness. One stays in the present, observing rather than responding. Halting a reaction allows for the exploration of alternative perspectives. In a calm, focused way we can tap into the current conflict and discover the resources we need to manage it. Becoming more mindful offers us more choices in dealing with our emotions. We can learn to replace our established trigger responses with new habits and to interrupt that cycle of negative thoughts by just putting them on hold and reeling them in. Once we do that we can break the problem up into smaller parts and spread them out so they won't seem so overwhelming to us. Sometimes we can control our anxious state by offering our minds a momentary distraction, long enough to allow the anxiety to pass. Mindfulness will help us become more resilient, but it does not require that we force our will into a state of positivity. Mindfulness is also acceptance that some degree of anxiety will always be normal for us, particularly when stressors are unfamiliar and unpredictable. Learning how to keep our distress thermometer at a fairly comfortable degree should be our self-care goal.

If adjusting to our cancer is the goal of our care plan, we can claim successful adjustment if we can minimize its disruptions. Are we able to manage specific cancer-related problems as they arise? Can we regulate our emotional distress? Have we remained active in ways that continue to hold meaning and importance for us? Adaptation to a chronic cancer is ongoing, and we may need the help of a professional at any given point in time. Even after successful treatment it's not unusual to find distress heightened and vulnerability renewed.

Discovering a balance between positive expectations and ongoing fears can be achieved in therapy. To take care of yourself also means to seek help or direction from others when needed. To seek guidance and support while exploring and adjusting to a life with cancer is a positive step to take at any point. Ideally, the counselor you choose should be skilled in psychotherapy with a solid background in oncology therapy. Many cancer organizations or cancer centers can offer a recommendation for services. Connectedness is key, and the initial consultation should help you determine if the therapist and the type of therapy offered will suit your needs. It's not unusual if family therapy sessions are recommended according to your particular situation. Antidepressants or anti-anxiety medication may be prescribed for temporary or even long-term relief of symptoms. Group therapy offers a supportive environment with group members who have the same cancer concerns. Self-help groups function under the control of their members and help foster hope and confidence in those who are struggling. There are also therapeutic groups led by a trained professional assisting and directing the group and offering supportive feedback.

In summary, we have at our disposal an array of methods to explore or from which to select in formulating a self-directed care plan. I've included only some of the popular and possibly more traditional techniques. I make no recommendation for one approach over another. We are each unique, and this simple fact means that the appropriate mode of self-care varies from individual to individual. My only advice is to find what helps you directly and keep doing it! If it stops helping, seek out other approved mental health alternatives that will offer the well-being that you are entitled to. Thankfully, our treatments can offer us many more years of active living. Our own self-care can significantly influence the quality of those years.

IWMF member Wanda Huskins is a behavioral health RN. This article is based on her professonal experience but is not intended to to be a substitute for professional medical advice. Wanda reminds us to always seek the advice of our oncologist or qualified health care provider regarding cancer-related issues

Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. If you have something you'd like to share with your fellow WMers, please contact *Torch* editor Alice Riginos at *ariginos@me.com*

IN THE TORCHLIGHT

BY LISA HERMANN, IWMF MEMBER

If I have learned anything since my 2010 WM diagnosis, it is to regularly challenge any school of thought one may have, no matter how convincing our 'set in concrete' thoughts may be. Traveling to Borneo a few months ago showed me just this. Let me share my Borneo story with you.

I was quite the nomad prior to diagnosis but had rigidly decided that keeping away from exotic developing countries (those vastly different from my Western lifestyle) was the best long term choice for my my physical well-being—and thus avoiding and thus avoiding unnecessary sanitary or bacterial issues, inoculations, and even unnecessary radiation scanning devices at airports.

I laid my nomadic soul to rest and went about my business, questioning my diet and exercise regime, my work load, my stress and negativity load, friends, family, and relationships, and also my emotional and psychological well-being—in all of which I made changes. The problem with pushing aside one's true spirit is that it rears itself to the surface at the least expected moment, and earlier this year my thirst for overseas travel became necessary for the nomad in me. I felt like it had been crushed from being ignored far too long.

Borneo had always been on my list of fave destinations to visit. Everything breathed culture when I thought of it. Price-wise it was a ridiculously cheap holiday. It also scared me. Trekking in forests, potential mosquito and snake bites, possible rabies, food poisoning, dirt and disease concerned me, but something egged me on. Did I wish to live a life based on 'what if's' and fear? Or, did I want to live a life based on making educated choices? I was a Wallie at 37. Still very young. Still very free spirited.

I researched as much about Borneo as I could. I understood the consequences of any choice I made. After a few more days of deliberation, I broke the news to my mother that I had booked the ticket and I was going within two weeks. I was even equipped with the right lines to say when her despair and concern became somewhat intensified. But had I not chosen to stick with my decision, my spirit—at some time in the future—would have broken, depression most likely would have kicked in, and this probably would have killed me earlier than anything WM would do.

Borneo (Sabah) was everything I had read about and more. The plethora of different fresh and healthy foods was magical, the generous spirit of the locals I met along the way blew me away. Fellow backpackers were all too open about sharing their experiences with me and telling me the best spots to visit. Seeing an orangutan in the wild, a species nearing extinction, was the tourist's highlight for me. I wept for days after knowing that I had seen a living thing so unfortunately very rare, just as I wept as my bus drove through kilometers of the palm plantations that are overtaking the beautiful environment for which Borneo is renowned. My mind was even further opened to the Muslim culture. As a woman traveling solo, I thought about how fortunate I am to have the freedom back home to choose whatever I want most of the time and, out of all Western luxuries, a good education.

I met people who were both sicker and healthier, richer and poorer than I, I heard and saw things I would not have otherwise seen. I learned about Borneo's politics, environment, and culture and shared my new knowledge with others back at home. I became more self-reliant on the trip, less fearful about making bolder life choices, and I also had time to be more aware of my body's requirements and rested when I needed it.

Traveling to Borneo was more than just a holiday, it was a real wake-up call to not let my diagnosis take over the way I viewed the world and how I conducted myself in it.

As this issue of the Torch *goes to press, Lisa is off again! This time to Vietnam, Laos, and Cambodia. Her account of the bold decision to satisfy her own inner call reminds us that while WM is often thought of as a disease of the elderly—or perhaps of 'those advancing in age'—not all Wallies have had the chance to reach middle age before diagnosis. Their concerns need to be voiced more regularly in our publications.*

In the Torchlight is a new column for WMers of all ages to share personal stories, special moments, events, or achievements that made you stop recently and reflect on your strengths and good fortune. Won't you share them with the Torch*? Our pages are full of stories of awards, accomplishments, successful treatments, new adventures, strength of character. We hope to include this column in each issue, but we need contributions. Write to your editor if you have a suggestion at ariginos@me.com.*

COOKS' HAPPY HOUR

BY PENNI WISNER

Everyone always wants to know how to eat more healthfully. It should be simple but so many voices have so much advice that confusion results. This spring, as fresh vegetables and fruits reappear in the markets, is as good a time as any to recall Michael Pollan's seven word summation that will take you immediately toward your goal of a healthy diet (provided that is your goal): Eat food, not too much, mostly plants. (Thank goodness cocoa is a plant!)

Food, by his definition, is anything your grandmother would recognize as food. And/or anything with only five, easily recognized ingredients on its label. There are exceptions, of course, for instance those new, "super" yogurts with ten active cultures when each is listed as a separate ingredient.

In 2012 I participated in several nutrition-and-demonstration presentations for cancer groups. A registered dietician would give the lecture while I did the fun part—made the food that brought all those concepts and theories to tasty life.

As the lecturers made their points I looked over the vegan buffet laid out for the participants. Eat vegetables: bowls of them lined up ready to stuff veggie wraps. Eat plenty of leafy greens: kale chips with coconut and nutritional yeast. Whole soy. Organic edamame beans. Whole grains: whole-wheat flatbread and quinoa. Nuts and seeds: yup, roasted pumpkin and sunflower seeds. Omega-3 sources: sure, flax meal and chia seeds. Antioxidants: check! Colorful fruit and dark chocolate. Homemade salad dressings for those who preferred to turn all those vegetables into a salad instead of a sandwich stuffing. And gluten-free wrap alternatives: rice paper wraps, nori sheets, and collard leaves. (I will describe those in more detail later.)

For people like us WMers, a diverse and fascinating group (don't you think so?), our primary concern (I am making assumptions but I hope you will agree with them) is to increase or maintain energy levels and to, if possible, prevent or delay recurrences. This is best done by following Pollan's common-sense advice. (Can you tell he's my hero?)

Nutritionists tell us to eat five (1/2-cup) servings of vegetables per day. To divide our plates in fourths and cover half with vegetables, one-quarter with protein, and the remaining quarter with whole grains. I ask you: Does this sound fun? Delicious? Easy?

My first line of attack to solve the "eat more vegetables" case is: Attitude. Eat your vegetables raw. Exceptions allowed: Vegetables you cannot digest and mushrooms, which must be cooked. Raw zucchini is sweet and crisp. Baby butternut squash is tender. Raw beet has less "beet-iness" than cooked beets and is very crunchy. Those who live around the Mediterranean (that hotbed of healthy diets) eat thinly sliced, raw artichokes. Now that asparagus season is upon us, slice it very thin and eat it raw. Unless you cannot digest them, eat fava beans raw. You get it, right?

The second best way to deal with stacks of vegetables is with good equipment: a very sharp chef's knife, a hand-held mandolin/slicer, a hand-held julienne slicer, and a spiral slicer (Benriner is the manufacturer of the one I have but new ones are just being released). With all, you must watch your fingertips. Otherwise, these tools help you slice, dice, and julienne quickly and evenly. The spiral slicer fascinates seminar members every time because it turns carrots, cucumbers, zucchini, beets, and radishes (to name a few) into thin, curly threads. A little vinaigrette (homemade, remember?) and you have an amazing salad.

Luckily, it is becoming easier and easier to eat in a healthy manner. For example, while shopping for a cancer-survivor retreat day, I found fresh, organic pea and radish sprouts at Trader Joe's. Look at sprouts as "the little engines that could," seeds developing their full potential—growing. Therefore, when your onions and garlic sprout, cook those little green shoots. On the other hand, divide and plant, do not eat, sprouted potatoes!

For one event, I sprouted some organic dried chickpeas. All it took was an overnight soak and then leaving the drained chickpeas on paper towels (so they remain humid) in a covered container for a day. (Eat the sprouts when the growing tip is only about 1/4-inch long.) You can eat them without further cooking or roll them in spices, herbs, and oil and bake them until crispy for a cocktail snack. Or make hummus with them. Sprout wheat berries the same way and cook them into cereal—the sprouting process has the added benefit of shortening the cooking time—or use them for grain salads, as a salad add-in, or in breads and muffins.

Trader Joe's also offers bags of chia seeds, the new omega-3 super star on the grocery aisle. They joined their brothers in omega-3 land, flax seeds, which have been on shelves for some time. Bob's Red Mill sells flax meal but I prefer the oily richness of freshly ground seeds to the convenience of the meal. How to use these nutrition boosters? Since the events were buffet lunches, the chia seeds and flax meal were there as veggie-wrap add-ins as well as salad toppers. Or add them to bread and muffin batters, as toppings for salads and soups. Or just let them soak in a glass of water until it gels. A sort of omega-3 bubble tea!

When I demonstrated using collard leaves as wraps instead of bread, they gained an enthusiastic audience. It's the same idea as using grape leaves. Now that I think of it, stuffed grape leaves are a wonderfully healthy snack to take out to watch the sunset with your glass of wine. To make the collard wraps, choose the biggest leaves you can. Trim the collard stems at the base of the leaves. And then shave the stem on the underside of the leaf to get it as thin as possible. Finally, blanch the leaves, one by one, in a large shallow skillet of salted water for 30

Cooks' Happy Hour, cont. on page 23

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

CANADA

Calgary, Alberta

The Calgary group continues to grow. **Cam** and **Jane Fraser** hosted eighteen people at their home in mid-January, including two new patients and their spouses. We have outgrown our space and are looking for a location where we can meet. Fortunately, one member lives in a complex that has a common room that may serve. After a quick introduction of the new members, the meeting followed a round-table sharing format with considerable interaction as members discussed both recent treatments and treatment options under consideration. Afterwards, we watched the latest version of Dr. Morie Gertz's "Garden" video. It was the first time that several of the attendees had seen this easily understood primer on our disease. During a discussion about the upcoming IWMF Ed Forum in San Diego, one couple declared they would attend and several others expressed strong interest. A speaker meeting is planned for the spring. **Stu Boland** and **Cam Fraser reporting.**

AUSTRALIAN SUPPORT GROUP

Action continues in Brisbane in the guiding hands of Nicole Douglas at the Leukaemia Foundation of Queensland (LFQ). It is truly great to have her input and note the growing number of WM patients who make direct contact with her office in Brisbane and who get personal support and also access to the wonderful patient and family care facilities at LFQ.

This year's patient luncheon meetings are set for April 23 and October 23. Everyone is welcome, the conversation is always interesting, and the people are nice, they are WM'ers after all. Peter Carr keeps a watchful eye behind the scenes, although sometimes from across distant oceans. As everyone knows, it is crucial to live well and enjoy what life has to offer us, whilst also giving a little of ourselves to help others.

The Sydney event for the year will be a special for all of Australia and New Zealand: The Waldenstrom Macroglobulinemia Forum, to be held on the afternoon of October 25 at Concord Clinical Centre, Concord Hospital, Sydney. The Forum will be held in conjunction with a wider program of interest to patients and caregivers. The keynote speaker will be Dr. Meletios Dimopoulos. Dr. Dimopoulos is Professor and Chairman of the Department of Clinical Therapeutics at the University of Athens School of Medicine, Athens, Greece. He is a recipient of the Robert A. Kyle Award for outstanding contributions to Waldenstrom's macroglobulinemia and also a member of the IWMF Scientific Advisory Committee. Dr. Dimopoulos will enjoy saying hello to some of his local patients. The program will also feature a panel of Sydney consulting hematologists including: Professor Joyce Ho, Vice President of the Hematology Society of Australia and New Zealand; Professor Douglas Joshua, Senior Staff Specialist in Hematology at Royal Prince Albert Hospital; and Associate Professor Judith Trotman, Consultant Hematologist at Concord Hospital.

Patients, family members, friends, and medical advisors are all invited to the Forum. Andrew Warden, member of the steering committee, is always full of answers, questions, and ideas. Please look for updated program information at *www.wmozzies.com*. This site also features the local contact details for our WMOzzies team. **Collin Perrott reporting**

Waldenström France Association

The annual meeting of the Waldenström France Association will be held in Paris on September 28. We will meet at the Plateforme Maladies Rares, Hôpital Broussais, 102, rue Didot, 75014. The speaker will be Dr. Véronique Leblond, an important figure in the field of French hematology and a member of the IWMF Scientific Advisory Committee. For program details and registration information, please contact *waldenstromfrance@live.fr* or phone +33 -0-490 870 930. **Nicole Bastin reporting.**

Cooks' Happy Hour, cont. from page 22

seconds to a minute. Just enough to make them pliable. Drain well. Separate each leaf with paper towel or wax paper, seal in a plastic bag, and refrigerate up to several days.

Recently, a client asked me to help her plan menus. In thinking about it, I think the best advice is: "Every day eat a rainbow of foods." All the better if they come in a variety of textures. If you really must be technical about it, all those colors betray the presence of phytochemicals—powerful agents on the side of health and vigor. These appear in particular abundance in herbs and spices. Another way to add great taste (oh yes, and health benefits) to all your cooking. Some of my favorites are za'tar, a blend of mountain thyme, sesame, and sumac; ras el hanout, full of warm (anti-inflammatory) spices; and vadouvan, a curry mix including lots of garlic and shallots.

And, in spite of, or in addition to, all this talk of smart, healthy eating, for me the primary reason to eat in this way is the sheer beauty and taste of great ingredients. My founding partner in this endeavor, Nancy Lambert, summed it up best:

Our motto: Eat Well to Stay Well

SUPPORT GROUP NEWS

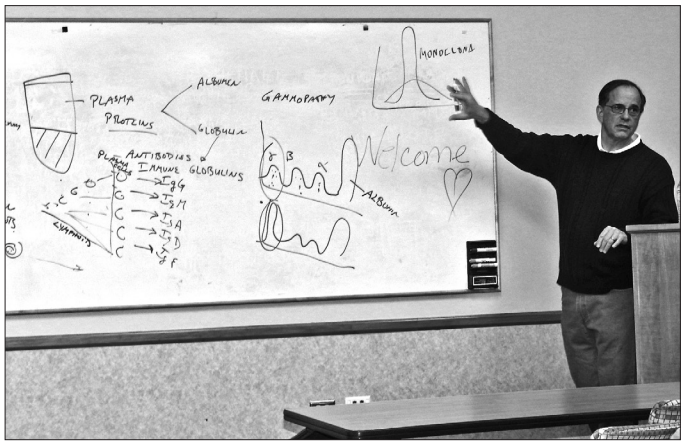
EDITED BY PENNI WISNER

CALIFORNIA

Sacramento and Bay Area

Because the 2013 IWMF Ed Forum will be in California, the theme of the February meeting was "IWMF Ed Forum 101" with an emphasis on how easy it would be to attend. And how informative and how much fun. **Terry Rossow** had assembled short video clips from previous Forums with Drs. Kyle, Gertz, Ansell, and Treon. The videos allowed participants to attach faces to the names of these leaders in treating and researching WM. Five attendees of the last Forum in Philadelphia shared their experiences. **Tom White** was especially eloquent in describing how helpful the Forums have been to his understanding of Waldenstrom's. They all stressed how presenters at the Forums work hard to make WM tech-speak more understandable to laymen. After a break to enjoy finger foods, members traded stories of their personal journeys with Waldenstrom's. By the end of the meeting, many of the Northern California group planned to attend the Ed Forum for the first time this year.

COLORADO



Dr. Stuart Lind delivered a dynamic talk on WM and filled the board with key notations as he spoke.

The Rocky Mountain support group met February 23 at the new University of Colorado Cancer Center in Aurora. Dr. Stuart Lind, a hematologist/oncologist from CU Health Systems, was our speaker. He led a very lively discussion about our "burning and unanswered questions related to WM" with lots of clever examples and drawings on the board. We all thought we learned a lot and will invite him back again! We had 24 attendees on a beautiful day, right between all of our snowstorms, so the weather was perfect. We did have to maneuver our way through the huge buildings on the new CU Med Center campus, so the walk was a little challenging for some. We had a great breakfast for all, supplied by our partner, Lori Apple, of the Denver Leukemia & Lymphoma (LLS) chapter. We had one more newly diagnosed patient and welcomed her with lots of ideas and support! We plan to meet again over lunch on April 20, during the Rocky Mt. Blood Cancer Conference, with a lunchbox chat with Dr. Jeffrey Matous of the Colorado Blood Cancer Institute.

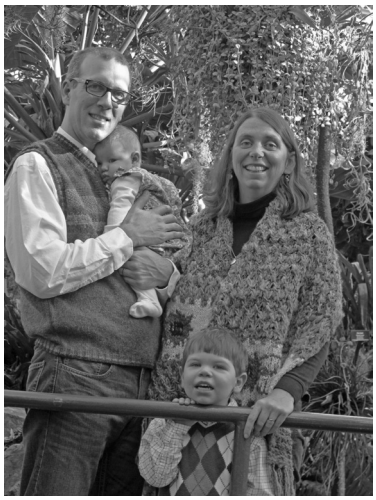
FLORIDA

Ft. Lauderdale Area

Twenty-six people attended the fall meeting in October for a traditional, round-table discussion in which everyone participated. The group thanked **Phil Lewis,** co-leader, as he officially stepped down from his responsibilities. Plans are in process to hold the next meeting in the spring of 2013.

ILLINOIS

Chicago Area/SE Wisconsin



The newly-expanded Scofield family at the Garfield Park Conservatory in Chicago. Ryan (aka The Marathon Man), newest son Gridley, wife Krista, and son Arthur.

While the Chicago-area group has not met since fall, life for its members continues to be eventful. On the very day of the autumn meeting, October 20, **Gridley Scofield** was born to WMer **Ryan Scofield** and wife, **Krista McKim.** Gridley joins his older brother **Arthur** to increase the family to four. If you remember, Ryan, the Marathon Man, ran the Chicago Half Marathon last year, raising $7000 for the IWMF (see the October 2012 *Torch* pages 16-17). Ryan now plans to run the full, famous Chicago Marathon in the Fall of 2014. Not bad for a WMer in his late 30's! Ryan is on track to beat group leader Don Brown's goal of skiing Steamboat in 2018, his 75th year. It is amazing how WMers can thrive physically even with this indolent disease. Maybe all that is needed is to take the next step, whether it is a simple walk around the block or a more challenging marathon. To hear more about the future of WM treatments and research, join the group on April 20 to hear from Rush University Medical Center's Dr. Stephanie Gregory. Dr. Gregory, who has extensive experience in hematology, spoke to the group several years ago. The presentation will be at the usual location: Advocate Lutheran General Hospital in Park Ridge. Hopefully, members will be able to congratulate the Scofields in person as well.

INDIANA

Chris Fausel, a registered pharmacist, spoke to the group at the March meeting held at the LLS offices in Indianapolis. He discussed both short-term and long-term side effects of chemotherapy and suggested ways to manage them. The presentation engendered a great conversation among all the members and their caregivers. The long-term effects of chemotherapy were of particular interest to the group,

Support Group News, cont. on page 25

many of whom are on watch-and-wait following previous treatments and anticipate needing treatment again at some point in the future. The meeting also featured round table introductions and status updates as well as warm welcomes to new members. Claire Kammen of the Indiana LLS provided breakfast snacks and lots of good coffee. As usual, there was candy on the table for all to enjoy. The group thanks the LLS for its ongoing support. The meeting schedule includes three meetings per year, usually spring, summer, and fall, on a Saturday morning from 10 am to noon.

NEW ENGLAND

Boston

Early in 2013, the New England WM support group got together twice. The group met on a cold but sunny Sunday in January at the Dana-Farber Cancer Institute. The support group leaders, **Judy Christensen** and **Lynn** and **Joe Mara,** led a round table discussion during which WMers and caregivers shared experiences and sought information from others present. Members were inspired to learn that two "long-timers" had their diagnoses 17 and 14 years ago. Another WMer has been on watch-and-wait since diagnosis eight years ago. Others shared their experiences with clinical trials; while for some the trials went well, for others there were some side effects. In March a great crowd came out to hear Dr. Steven Treon of Dana-Farber give his annual "State of the WM World." Dr. Treon discussed the latest advances in research and the newest drugs being evaluated. Of great interest for the WM community was the growing understanding of the role of the L265P mutation in the gene for MYD88. This mutation was discovered through the efforts of Dr. Treon and his group at DFCI and was partially funded by the IWMF.

NEW YORK

New York City

The extremely well-informed, articulate participants in the New York metro-area group refused to let a cold January day discourage their meeting. They have succeeded so well in educating themselves that sitting in on a gathering can feel a bit like attending an abbreviated version of the IWMF Educational Forum. Several newly diagnosed WMers joined the throng, arriving with many questions, including where to find the experienced doctors and what treatments are working best. It is fair to say that they left calmer, more knowledgeable, and, most importantly, more hopeful about their futures. The members look forward to these new patients becoming regular members who will continue to share their Waldenstrom journeys. The group would love to welcome any WMer visiting NYC on a Sunday meeting day to join in a high-energy, upbeat experience.

OREGON/SOUTHWEST WASHINGTON

The support group met on a rainy, cool, winter day in January, but the warmth and collegiality of the group inside made up for the gray skies outside. Twenty-seven members gathered to greet each other, share lunch, and hear a presentation by Dr. Stephen Spurgeon, an oncologist and researcher at the Knight Cancer Institute of the Oregon Health and Sciences University. His talk, "News You Can Use: An Update on Waldenstrom's from the Latest ASH Conference," included a review of WM basics, detailed some of the latest drugs being used for treatment, and presented the positive and negative aspects of each of the options available at present. He conveyed a hopeful message as he discussed the continuing advances made in understanding lymphoid cancers in general and in WM specifically. Of particular interest was the impact of the MYD88 L265P mutation on the pathways of a WM cell. Identification of the mutation by Dr. Treon's group at Dana-Farber was made possible by whole genome sequencing. The implication for treatments is centered on finding effective ways to disrupt the impact of the mutation in order to cause the death of the WM cell. Dr. Spurgeon communicated the highly technical information in a way that the group was able to understand. The questions were many and the discussion was lively. Members felt encouraged and hopeful for the future. The next meeting is planned for April 28 at the Fairfield Inn and Suites, 6100 Meadows Road, Lake Oswego, OR. The local chapter of the LLS partners with the IWMF chapter to host the meetings. The LLS secures the meeting place, helps to coordinate speakers, aids with publicity, and provides lunch for the group.

PENNSYLVANIA

Harrisburg Area

The group members met early in February to discuss articles from the IWMF ***Torch*** newsletter. They also exchanged information on their current status and treatments and brought each other up to date on absent members. **Don** and **Kate Wolgemuth** provided light snacks to fuel the energetic sharing among special friends. And **Terrie Eshleman** brought Russell Stover Private Reserve Sugar Free Chocolates. They are 60% cacao and have raspberry or vanilla caramel filling (a great discovery!). Plans are afoot to meet again on the third Sunday in May, again at the Messiah Village at 2 pm.

Philadelphia

Seventeen people and one dog met at group leader **Karen Pindzola's** house in early December. The topic, "how to keep from getting sick" came up, probably because flu season was beginning and WMers are always a little cautious about catching something. Everyone had a suggestion. Wash hands often. Use hand sanitizer if you can't wash. Avoid sick people. Use a face mask, particularly when using public transportation, trains, and planes. Watch out in the doctor's office—all those magazines, doorknobs, and most anything else in the waiting room. Don't be too tempted to hug your runny-nosed grandkids; wait until spring. Don't touch your face. Take a multivitamin every day. And on it went. In sum, WMers need to be aware of these things and do what they can, while continuing to enjoy a full life. At the March get-together, the group discussed the IWMF Patient Database and what it can do for patients. Enthusiasm fuels each gathering and after every one there is time for chatting and enjoying the goodies participants have brought along.

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THE LIFELINE

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

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

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Susan Gross
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David & Gail Smith

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Molly Frantz

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In honor of All That Volunteer For the IWMF:
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In honor of Keith Anderson:
Bev Anderson

In honor of Thomas M. Baker:
PNC Bank

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In honor of K. Edward Jacobi:
Ellen, Corine, Bill, Anthony & Nicholas Peifer

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Chris, Jen, Mike, Monte & Courtney Benecke
Robert and Sheila Benecke

In honor of Gail Jaye:
Matt Minner & Joy Jaye

In honor of Robert Kelson:
Cheryl Kelson Mulhall

In honor of Polly Kidd:
Joshua Kidd

In honor of Lynn Kingsbury:
Cathy Kingsbury

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In honor of Ruth Lizotte:
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Julie Moakley

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Kimmins Terrier Foundation, Inc.

In honor of Marjorie Oberlander:
Jill Oberlander and the Penn Oberlander Family

In honor of Gina Odell & Michael Smith:
Daniel Odell

In honor of the birthday of James Ortoleva:
Louise Stiller

In honor of the 50th Wedding Anniversary of James and Bette Ortoleva:
Gail Ahern

In honor of Mike Pennington:
Bob & Norma Pennington

In honor of Valerie Petelin's birthday:
Tom & Joy Lynn Schnell

In honor of Karen Pindzola:
Andrew & Lauren Courtney

In honor of Norman & Sharon Poteshman's 50th Wedding Anniversary:
Eran & Rochelle Panner
Larry & Maxine Speyer

In honor of Sharon Poteshman:
Ira & Sue Bernstein

In honor of Edie Prest:
Bill Prest

In honor of Barbara Richter:
Michael Richter

In honor of Alice Riginos:
Vasilis Riginos

In honor of Robert Rosencranz:
Holly Rosencranz

In honor of Susan Rubenstein:
John & Christine Bakalar
Ira & Sue Bernstein

In honor of Michael Sesnowitz:
Suzanne Horn
Craig Sesnowitz

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Ralph & Elizabeth Smith

In honor of Ron Smith:
Jana Perry

In honor of Elaine Van Bloom:
Fred & Dolores Pernerstorfer

In honor of Ubaldo Vitali:
Francesca Vitali

In honor of the anniversary of Mr. & Mrs. Ubaldo Vitali:
Celeste & Phyllis Fasone

In honor of Daryll Wartluft:
Todd Wartluft

In honor of Lisa Weldy:
Karen Ancel
Judith Weldy

In honor of Tom White:
Frank & Betty Clayton
Doug Falco
Matt & Jessica White

In honor of Ken Wierda:
The employees of the West Michigan MFP

In honor of Marcia Wierda:
Barbara Buist
Ruth Engelsma
Evelyn Hamberg
Judy Motman

In honor of Marcia & Ken Wierda:
Harlan Sprik

In honor of Galen Wilkinson:
Marvin & Jan Michael

In honor of Bob Zehner:
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In honor of Thomas M. Baker
by Frederick & Almie Baker

L. Michael and Rosalie Larsen Research and Member Service Fund
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Caroline and Harry McPherson Research Fund
In honor of Harry McPherson
by Samuel Schneider Foundation

Carolyn K. Morris Research Fund
In memory of Carolyn K. Morris
by Maynard Morris

WE GET E-MAILS

In a recent e-mail to the *Torch* editor, Paulette Owens wrote as follows:

"I was very impressed with the article on Waldenstrom's. I was diagnosed about 1 1/2 years ago and am now in remission. But my vision has been terribly compromised. I had a corneal transplant about 10 months ago and the IOP is very high. At this time, my surgeon has not decided whether or not a replacement cornea is in my future.

I was not aware of the effects of this rare disease on the eye, and this article was a 'real eye-opener' for me.

Thanks for this insightful article."

The 'eye-opening article' Paulette refers to is the Doctor on Call article written by the IWMF's own Dr. Maureen Hanley which appeared in the January *Torch* of 2011 (issue 12.1) pages 1-5.

Providing a thorough overview of the eye problems that a WM patient may encounter, this article has been frequently cited on IWMF-Talk for the value of the information it sets forth. The article is available online at the IWMF website: *iwmf.com/docs/Torch%20%20Jan%202011.pdf*

Thanks to you, Dr. Maureen, for such a valuable article!

DID YOU KNOW?

Now you can download our booklets from our website!

You don't have to wait several days to receive a booklet or CD from the office or pick one up at the Ed Forum.

Go to *www.iwmf.com* and click on either IWMF Services or IWMF Library.
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It's fast and it's easy!

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IWMF is a 501(c)(3) tax exempt non-profit organization
Fed ID #54-1784426

Change of Address

Effective September 1, 2012, the IWMF Business Office moved to: 6144 Clark Center Avenue, Sarasota, FL 34238. Telephone, e-mail, and fax remain the same.

SAVE THE DATE!

IWMF 2013 Educational Forum
May 17 - 19
San Diego, California

The 2013 Ed Forum will be held in downtown San Diego at the Westin Hotel.
We've got a great rate at $129 a night, but availability is limited.
Visit *www.iwmf.com* for program.