

INSIDE THIS ISSUE

Doctor on Call:
Dr. Jeffrey V. Matous... 1

President's Corner 4

Ed Forum 2014..... 5

Diagnosis and
Management of
Anemia in WM 11

Nicole Bastin:
2014 Judith A. May
Volunteer of the
Year 12

In Memoriam:
Anne Greene 13

Michel Houche
May 1955 -
June 2014..... 13

International Scene.... 15

Warm Glow Giving 17

The Ben Rude
Heritage Society
Grows..... 19

Medical News
Roundup 20

From IWMF-Talk..... 22

Cooks' Happy Hour ... 24

In the Torchlight..... 25

Support Group
News 26

DOCTOR ON CALL: DR. JEFFREY V. MATOUS

WM: MANAGING THE SIDE EFFECTS OF TREATMENT



Dr. Jeff Matous answers a question from the podium at the recent IWMF Ed Forum in Tampa.

Jeffrey V. Matous, M.D., is presently Medical Director at the Colorado Blood Cancer Institute. After graduating from medical school from the University of Washington, he completed his residency in internal medicine as chief resident at the University of Colorado. Further training followed in hematology and bone marrow transplantation at the University of Washington and the Fred Hutchinson Cancer Research Center. Since 1994 Dr. Matous has worked in private practice in Denver, focusing primarily on the care of patients with indolent blood cancers. Dr. Matous is familiar to readers of the Support Group News column in the Torch for his frequent presentations to the Colorado support group.

In this article Dr. Matous shares much practical and effective advice for WM patients concerning the management of side effects from treatments for the symptoms of WM. The advice he offers is the result of more than twenty years of practicing the art of medicine to benefit his patients with indolent blood cancers.

A wise professor once told me in medical school that one could be the smartest doctor in the world but if his or her knowledge was not *effective* then its impact was dramatically reduced. In other words, physicians need to practice the *art* of medicine in order to optimally assist their patients. This article focuses on an important aspect of the art of medicine, namely managing the side effects, when treating patients with Waldenstrom's macroglobulinemia (WM).

The determination of side effects in WM patients can be quite challenging and tricky because many of the problems experienced by WM patients from the disease are similar to and overlap with some treatment side effects.

Let us begin by reviewing common symptoms of WM and then by asking how we define "side effects" of treatment. We then list the side effects commonly associated with WM (note that some of these side effects mimic symptoms of WM) and suggest ways that have been shown to be effective in our practice for the management of these side effects. In conclusion, we consider the side effects that may occur when a WM patient is treated with rituximab. Throughout this discussion, we repeatedly emphasize the need for the patient to take the initiative in communicating with the treating doctors and nurses.

WM Symptoms

There are certain recurring problems that physicians find in WM patients:

- Tiredness, often but not always the result of anemia
- Night sweats
- Headaches and dizziness (hyperviscosity or thickening of the blood from too much IgM)
- Various visual problems

OFFICERS & TRUSTEES

FOUNDER

Arnold Smokler

PRESIDENT EMERITA

Judith May

PRESIDENT

Carl Harrington

SECRETARY-TREASURER

Cynthia Ruhl

VICE PRESIDENTS

Guy Sherwood, M.D.

Elena Malunis

Michael Sesnowitz

BOARD OF TRUSTEES

Peter DeNardis

Marlyn Friedlander

Sue Herms

Marcia Klepac

Robert A. Kyle, M.D.

Ronald Yee

BUSINESS OFFICE

Sara McKinnie, Office Manager

IWMF SCIENTIFIC

ADVISORY COMMITTEE

Robert A. Kyle, M.D., Chairman
Mayo Clinic

Stephen Ansell, M.D.
Mayo Clinic

Bart Barlogie, M.D.
University of Arkansas

James R. Berenson, M.D.
Institute for Myeloma &
Bone Cancer Research

Morton Coleman, M.D.
Weill Cornell Medical College

Meletios A. Dimopoulos, M.D.
School of Medicine,
University of Athens, Greece

Stanley Frankel, M.D.
Columbia University

Morie Gertz, M.D.
Mayo Clinic

Irene Ghobrial, M.D.
Dana-Farber Cancer Institute

Eva Kimby, M.D.
Karolinska Institute, Sweden

Véronique Leblond, M.D.
Hôpital Pitié Salpêtrière, France

Gwen Nichols, M.D.
Hoffmann-La Roche, Ltd.

Roger Owen, M.D.
St. James's Institute of Oncology,
United Kingdom

Sheeba Thomas, M.D.
M.D. Anderson Cancer Center

Steven Treon, M.D.
Dana-Farber Cancer Institute
Mary Varterasian, M.D.

Doctor on Call, cont. from page 1

- Pain, numbness, or tingling in the extremities (neuropathy)
- Abnormal bleeding from the nose and gums
- Enlarged lymph nodes, spleen, liver
- Problems related to amyloidosis (see the article by Dr. Giampaolo Merlini in the *Torch* 14.2 (April 2013) pp. 1-4)

What exactly is a “side effect”?

The Food and Drug Administration (FDA) has a very specific definition of a side effect. This definition is broad and encompassing and therefore places a lot of responsibility on both the patient and the treatment team (nurse, doctor) to be in open communication with each other. According to the FDA, a side effect is:

“... any untoward medical occurrence in a patient or clinical investigation subject administered a pharmaceutical product and **which does not necessarily have to have a causal relationship with this treatment.** An adverse event (AE) can therefore be any unfavorable and unintended sign (including an abnormal laboratory finding, for example), symptom, or disease temporally associated with the use of a medicinal product, whether or not considered related to the medicinal product.”

In my view the important point to note is that WM patients should report any bothersome problem to their doctor and nurse and let us sort it out. Communicate. Even though we doctors often have high opinions of our own talents (at times even inflated) we do not read minds well, and it is imperative for patients to educate themselves about their disease, their treatments, and to **track and report** to their treatment team any possible side effects.

My lymphoma mentor, Dr. Oliver Press, used to say to his patients on treatment (and he could retire if had I paid him for each time I have used this phrase over the years), “If you have a problem now and did not have it before, we probably did it to you.”

Thoughts about how to communicate effectively with your team

Once you know what your treatment will be, gather as much information as possible about that treatment. What are the drugs? How are they given? What is the schedule? What are possible side effects? When do you need to call? This information should be written wherever possible. Utilize good websites (www.iwmf.com, www.lymphomation.org/, www.lls.org, etc). If possible bring other people with you to the treatment education session. Keep a journal or notebook – do **not** trust your

Doctor on Call, cont. on page 3



The IWMF *Torch* is a publication of:

International Waldenström's Macroglobulinemia Foundation

6144 Clark Center Avenue • Sarasota, FL 34238

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

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

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

EDITOR

Alice Riginos

ASSOCIATE EDITOR

Sue Herms

SUPPORT GROUP NEWS

Penni Wisner

CULINARY EDITOR

Penni Wisner

INTERNATIONAL CORRESPONDENT

Annette Aburdene

IWMF-TALK CORRESPONDENT

Jacob Weintraub

SENIOR WRITER

Guy Sherwood, M.D.

CONTRIBUTING AUTHOR

Morie A. Gertz, M.D.

PHOTOGRAPHERS

Peter DeNardis, Dave Kirby,
Jack Whelan

FORMATTING & PRODUCTION

Sara McKinnie

TORCH ADVISORY PANEL

Carl Harrington, Robert Kyle,
Judith May, Guy Sherwood

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

memory. When complicated information comes fast it can resemble drinking water from a fire hose. Ask your team how to anticipate and manage the most common side effects of treatment.

OK, so is all treatment “chemotherapy”?

I define chemotherapy, loosely, as any approved substance we put into our body to try and kill cancer cells. The types of chemotherapy are changing, and the side effects from treatments are quite different one from another. Chemotherapy has evolved dramatically over the decades. To be sure, we still use some drugs that have been in use for as much as fifty years to treat WM and other lymphomas (prednisone, cyclophosphamide, vincristine, doxorubicin). Even just a few years ago a drug called fludarabine (approved in the early 1990s) was a mainstay of WM treatment. The standard chemotherapy drugs we use now such as rituximab (used widely since the late 1990s), Velcade/bortezomib (in use since 2003), and bendamustine (in use since 2008) have very different side effect profiles from their predecessors. In 2014 we are also at the cusp of an era where increasingly chemotherapy will be in the form of a pill or capsule!

For WM patients there are so many different treatment options that to review them is beyond the scope of this article. One can review them in IWMMF Ed Forum talks or by visiting the NCCN (National Comprehensive Cancer Network) website at www.nccn.org/professionals/physician_gls/PDF/waldenstroms.pdf

Common, general side effects from chemotherapy

Even though certain treatment side effects are fairly common for different treatments, it is very important to know the most common side effects for **your** specific treatment. Before you start on any treatment, your doctor and nurse should discuss the potential risks and benefits of the treatment with you. This always happens when you are treated in a research study or clinical trial and should happen with every treatment. This is called “informed consent.”

Some common chemotherapy side effects and recommendations for management are:

- Nausea or vomiting. We have great medicines to prevent or treat nausea these days.
- Constipation. Stay ahead of this with stool softeners, watching your diet, and exercise.
- Diarrhea. Certain over-the-counter remedies such as loperamide usually help.
- Low blood counts. Be aware of your white blood count due to increased infection risk.
- Certain treatments increase the risk of shingles. Ask your doctor about use of an antiviral. Get your flu vaccine. Some patients who are subject to severe infections and low levels of antibodies such as IgA and IgG may benefit from IV gamma globulin infusions.

- Hair loss (increasingly rare).
- Fatigue. Fatigue is the toughest symptom to sort out since fatigue can be due to WM and/or treatment. Exercise and get rest (but not too much – keep naps short) and your fatigue should diminish as your disease recedes.
- “Chemo brain.” Exercise your brain just like you would your muscles – use it! If this condition continues to be bothersome, most clinics have access to psychologists who can help.
- Peripheral neuropathy. PN can be caused by the disease itself (the effect of IgM on certain patients) or by certain chemo drugs (bortezomib, vincristine, thalidomide). For prevention of severe neuropathy, the best strategy is to report any symptoms quickly to your treatment team. There are prescription and nonprescription remedies, and every clinic has its own recommendations.
- Anxiety and depression. These are common problems, worsened by steroid medications such as prednisone or dexamethasone. There is a lot in the way of support and help out there, and many patients benefit from prescription medications.

We should talk in more detail about rituximab

In almost all treatment situations we utilize a drug known as rituximab (Rituxan), which is a monoclonal antibody, a type of “targeted” therapy. In some instances rituximab may be used alone, but increasingly it is combined with other chemotherapeutic agents.

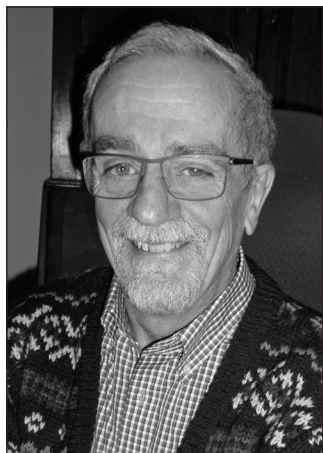
Rituximab has certain side effects, which are more pronounced and indeed unique in WM patients.

Any patient treated with rituximab, administered over several hours in a day by vein, may have as a side effect an allergic reaction whereby patients experience fever, chills, shakes, hives or even more severe problems such as breathing trouble, low blood pressure, and anaphylaxis. For reasons just being worked out by researchers, these allergic reactions appear to occur more frequently in WM (up to one in six patients) and to be more severe. For the majority of patients who experience allergic reactions to the drug, rituximab can still be given by adjusting preventative medications for the infusion. Some patients, however, simply cannot tolerate the drug no matter which preventive measures are taken. For such cases we can use ofatumumab as a substitute antibody.

A second unusual reaction to rituximab is a “flare,” whereby the IgM level can **increase** during the first few weeks of rituximab therapy, sometimes to levels that cause the blood to thicken (hyperviscosity syndrome), making patients ill. This flare reaction is usually limited to patients with IgM levels above 4,000 or 5,000 prior to rituximab treatment and can be mitigated by combining the rituximab with other



PRESIDENT'S CORNER



When I was a kid, I learned that 'more' was good but that 'way more' was usually better...especially when it applied to presents from Santa Claus or desserts. I also learned that this does not apply to things like Brussels sprouts or being sick.

As we head into the second half of 2014, we're lucky that the 'way more' concept applies to the world of WM

in so many ways. What do we have 'way more' of that's good? We have:

Way more and better treatments: In 2000, there were 4 treatments for WM. Now, including drugs in clinical trial, there are over **30**. Not only do we have more treatments, we have **better** treatments. Today's newer treatments for WM are much more effective and have fewer side effects than the treatments of the past. That's a big step while we wait for a cure.

Way more clinical trials: As avid readers of the *Torch* or participants in IWWMF-Talk know, there are more clinical trials now for WMers than ever before. But did you know that there are currently **98** clinical trials in the U.S. alone that include WM as a condition?

Way more dedicated researchers: In September of 2000, 19 researchers gathered for the First International Workshop to discuss coming to consensus on a basic understanding of WM, how it is defined, how it is diagnosed, and what the prognosis factors would be. This summer, in August of 2014, over **250** WM researchers will gather in London for IWWM8, the Eighth International Workshop on Waldenström's Macroglobulinemia, coordinated by Dr. Steven Treon.

Way more research: Since 1999, the IWWMF has invested over 7 million dollars in research into our disease. We now have WM cell lines, WM mouse models, WM tissue banks, an understanding of the genomics of WM, and much more. All of this research was funded by donations of WMers and their friends and family. In other words, by you!

Way more focused research: At our recent Educational Forum in Tampa, I announced a new partnership with the Leukemia & Lymphoma Society. In October, a select group of WM strategists will gather at LLS headquarters in White Plains, NY, to identify a Strategic Research Roadmap for WM. This roadmap will help us invest your donations in the best possible way in the future.

If you didn't attend the Tampa 2014 Educational Forum, you missed a great event (see page 5 and you'll see what I mean). Attendance was 284, up 30% vs. the previous year. And attendees loved the Forum, rating the event 4.81 out of 5. What did they love?

Meeting and talking to other WMers.

The expert speakers and their accessibility.

The information booths from the LLS, Pharmacocyclics, Idera Pharmaceuticals, Gilead Sciences, Rare Patient Voice, and the research posters with their layman-friendly conclusions.

Those of you who missed meeting the experts, making new friends, and checking out the information booths can now go to the IWWMF website to see the slides from the presenters as well as videos of selected presentations under iwmf.com/services/ed-forum.aspx. Click on *Ed Forum Agenda* and then click on either *PowerPoint slides* or *videos*.

What's ahead in the coming months? **'Way more!'**

The Fifth International IWWMF Doctor-Patient Forum: The Forum will take place in London on August 17. Presenters will share the breaking news from IWWM8. Roger Brown of the WMUK is coordinating the Forum with Dr. Shirley D'Sa. Visit the WMUK website for more information wmuk.org.uk/news-and-events/events

The twentieth IWWMF Educational Forum: Be sure to put the date on your calendar now. The Ed Forum will be held in Dallas, Texas, on May 1-3, 2015, at the Hilton DFW Lakes Executive Conference Center near the Dallas-Fort Worth Airport. A Texas-sized celebration of twenty years of WM progress is planned. Please come!

A new and improved (i.e. 'way better') IWWMF website: Keep your eyes peeled for the launch early this fall when iwmf.com will be accessible from all of your mobile equipment. It will then be easier for you to keep up with what's new in the world of WM.

To continue our momentum in both Research and Member Services, we need your help **now**. WM is an orphan disease. We don't receive government funding or a lot of outside support. What we are able to do is dependent upon you. We currently have more good research proposals than we can fund. Would you please give as generously as you can to both the Member Services Fund and the Research Fund? And ask your friends and family to donate too. What we can accomplish is entirely up to you.

Let's work together to make sure that 'way more' good things continue to be available for WMers everywhere.

Stay well!
Carl



ED FORUM 2014

BY SECRET WALLIE

The 2014 IWMF Educational Forum took place May 16-18 at the Marriott Renaissance Hotel in Tampa, Florida. At this annual event dedicated to the disease Waldenstrom's macroglobulinemia, 284 attendees gathered to hear from leading researchers, from experienced clinicians, and from veteran WM patients. Participants attended sessions about recent advancements in understanding the genetic basis of the disease, current directions of research aiming at improved treatments and ultimately a cure, advice from clinicians regarding the up-to-date line-up of drugs they prescribe, and even "words from the wise" from veteran patients with a wealth of useful insights to share.



Friday morning walkers at Cypress Point Park.

Once again "our man at the Forum" Secret Wallie provided a stream of bulletins from Tampa on IWMF-Talk covering the days' events to keep those who could not be there apprised of all the rewarding experiences that attending an IWMF Ed Forum provides. The following article presents highlights of Secret Wallie's report ranging over the full two and a half days.

Ed Forum videos and PowerPoint slides

First, a word is in order about new services available this year for online coverage of Ed Forum presentations. Videos of four presentations are available in their entirety. The four presentations are those of Dr. Bruce Cheson (keynote speaker at Friday night's Ed Forum Dinner); Dr. Steven Treon (Saturday afternoon); Dr. Morie Gertz (Sunday morning); and Ask the Doctor (Sunday morning), a panel consisting of Dr. Gwen Nichols, Dr. Treon, and Dr. Gertz and moderated by Dr. Robert Kyle. Also available are the PowerPoint slides that accompanied the presentations delivered at the Forum. These slides provide the outlines shown on the big screen as the lecturer spoke and are very useful in following the main points of the talk and in keeping a grasp on the names and terms used in the lecture.

The videos and the slides are accessible on the website under iwmf.com/services/ed-forum.aspx. Click on *Ed Forum Agenda* and then click on either *PowerPoint slides* or *videos*. PowerPoint slides are not available for the four presentations that, as noted above, are available as videos.

FRIDAY MAY 16

Morning walk

For many folks who had arrived on Thursday, Friday began bright and early at 6:30 am when about 30 people gathered to participate in a 5 mile walk from the Renaissance Marriott to the beach at Cypress Point Park on Old Tampa Bay. Walkers shared stories and experiences, enjoying each other's

company along the way. The weather was a bit on the cool side but perfect for an brisk walk through a park studded with cypress and palm trees that led to a white sand beach. Participants agreed that this was a great and invigorating way to begin the Forum!

Opening session

The meetings formally began with an introduction from IWMF President Carl Harrington, who explained the program for the next three days. Carl had folks stand up in the audience based on whether they were newly diagnosed or caregivers and for veterans by their years of longevity. It was heartening to see many, many folks in attendance who have been WM patients for over 15 years!

Then the formal sessions began and we were off! Friday's program opened with topics selected with the newly diagnosed and their caregivers in mind, the basics, you might say, of WM. Of course, it is so essential for all of us to understand the basics that you might call these topics a WM refresher course for those of us who fall into the class of "WM veterans." First off, we heard from Dr. Rachid Baz (Moffitt Cancer Center, Tampa) who led us through "Hematology 101." Using layman's terms, Dr. Baz provided a thorough overview of all the basics that every WMer is sure to encounter as he or she takes those first steps to understand this disease and its impact.

Mary Turney, also of the Moffitt Cancer Center, focused on the caregiver. Speaking about the various aspects of the "continuum of care" (diagnostic phase, treatment phase, post treatment phase, recurrence, and end of life), her words brought home how demanding this role is.

Lunch was next (buffet style with lots of healthy selections – fresh salad fixin's were my choice) and then we hurried back

Ed Forum 2014, cont. on page 6



to join Dr. Christine Chen of the University of Toronto for “Traditional Therapies for WM.”

Dr. Chen’s presentation was particularly valuable to those recently diagnosed as it is likely that the first treatment decision for each will be to select among the options she discussed. Dr. Chen first covered the list of drugs that are currently used in single-drug therapy, and then she discussed the drugs used in combination regimens and what the standard combinations are. To complete the review she noted that stem cell transplantation is also an option.

Our next presenter, Dr. Peter Martin (Weill-Cornell Medical College) led us away from the traditional therapies and on to more recent developments when he spoke on “Novel Treatments for WM.” His presentation covered the different classes of the newest drugs that are being used cautiously, following testing in clinical trials. For details provided by Dr. Martin in this report, I’d suggest you take a look at his PowerPoint slides on the IWWMF website. Familiarizing ourselves with these new drugs and their terminology is our current challenge as Wallies, especially veterans who want to participate in treatment decisions.

The first day of Ed Forum 2014 concluded Friday afternoon with special breakout sessions focusing on drugs (ibrutinib, Rituxan, Velcade, bendamustine) and treatments (plasmapheresis and stem cell transplant).

Friday evening

Balmy Floridian breezes rustled through the branches of the palm trees in La Fuente Courtyard as attendees reassembled for the President’s Reception, which preceded the Ed Forum Dinner. The spacious courtyard provided plenty of room for folks to circulate and socialize while they enjoyed a beverage and the exceptionally delicious hors d’oeuvres.

On to the ballroom for dinner! I will make this one observation about the food served throughout all the meals at the Forum: It was fantastic!

After dinner, IWWMF President Carl Harrington gave his President’s Address, in which he eloquently explained the *Imagine a Cure – Seeds of Hope* theme by presenting the case for how far the state of WM treatment has come in the past decade and the promise that is forthcoming with novel treatments. The “seeds of hope” for a cure were represented by packets of Purple Coneflower seeds that were given to everyone in attendance. The seeds of hope will need watering and sunshine to grow – and, for all WM patients, that represents donations to fund further research to arrive at a cure.

Keynote speaker

The keynote speaker was Dr. Bruce Cheson (Georgetown University), who spoke about “The End of Chemotherapy.” Dr. Cheson gave a very informative and entertaining speech (which I urge you to see in the video on the IWWMF website – I know you will enjoy it) about the history of treatments for WM, issues

with regard to new drug development, clinical trials, and when and how folks can participate in clinical trials. Dr. Cheson’s optimism is contagious as he looks forward to the day in the very near future when we can all plant seeds of hope “in the form of grass on the grave of chemotherapy drugs!”

Interestingly, Dr. Cheson chose to close his talk by displaying an article clipped from a recent issue of *Wine Spectator* magazine stating that long-term wine drinking is linked to low lymphoma death rates! Incidentally, Dr. Cheson held on to a glass of red wine throughout his entire speech to further emphasize that fact.

Final observations on Friday

In between speaker sessions, and at the end of the sessions, one could easily spot patients in deep discussions with the doctors and other presenters both before and after their presentations. I continue to be amazed by the patience and concern exhibited by these very caring professionals. WM patients are truly blessed to have such wonderful persons working on our behalf!

It was also inspiring to see returning attendees re-connecting with fellow WMers who’ve also attended meetings in years past and to see first time attendees conversing intensely with veteran WMers throughout the day. The event took on an atmosphere of a family reunion, where each family member cares deeply about the well being of each other. One could feel the “seeds of hope” being planted in the hearts of all in attendance.

SATURDAY MAY 17

Breakfast

Breakfast on Saturday – and this is true for Sunday as well – offered an array of so many healthy breakfast foods that it was hard to make a choice. On both mornings I was surprised to find huge bowls brimming with blueberries, strawberries, and raspberries! A scoop of each to start the day!

Folks could be seen gathering at the breakfast tables in the outdoor courtyard to break bread (OK, eggs) together and share stories. At one table was the IWWMF-Talk gathering led by the talklist Manager Peter DeNardis to allow some face-to-face conversations between participants who may be online correspondents and pals.

DFCI Tissue Bank signup and buccal cell collection

Again this year, the folks from DFCI were on hand to register WMers for the Tissue Bank Study and collect their buccal cells (basically you swish some mouthwash in your mouth and spit it back into a cup so they can collect cells for analysis). Hopefully, we’ll get to see some interesting findings from their tissue and questionnaire study!

Saturday morning program

Saturday was an amazing day. One outstanding presentation followed another (including those by new faces at the podium



AN ED FORUM ALBUM: TAMPA 2014



as well as the “rock stars of WM research”) and left us in the audience working hard to absorb all the important new information and terminology. Once again I note that the content of the PowerPoint slides shown for the Saturday presenters are online at our website and refer you to the slides to follow the content of the presentations from all three days of the Forum.

First speaker of the day (who just happens to be our Doctor on Call for this issue of the *Torch* – see page 1) was Dr. Jeffrey Matous (Colorado Blood Cancer Institute). In “Managing the Side Effects of Treatment,” Dr. Matous reviewed the wide range of ways that treatments may affect the patient. From his own very active practice he provided a wealth of tips and advice to lessen the impact of the drugs we count on to treat WM.

Dr. Robert Kyle (Mayo Clinic) spoke next on “Indications for Treatment.” Dr. Kyle, the “godfather” of hematologists worldwide, reviewed for us the indications that call for treatment to be initiated, and, on the other hand, he cautioned that one does not want to over-treat and probably treatment is not required if the patient is not symptomatic.



Dr. Gwen Nichols and IWMF Trustee Ron Yee

Dr. Gwen Nichols (Hoffman-LaRoche) addressed clinical trials from the special perspective of a hematologist who has treated WM patients and who now works in the pharmaceutical industry. To jump to her conclusion, Dr. Nichols closed by saying that it’s important that the WM community advocate for and help fund research and clinical trials for WM and in this way to support the IWMF. Doing this allows researchers to approach the pharma industry about testing drugs on WM patients. “And it truly wouldn’t happen otherwise,” to quote Dr. Nichols. On the other hand, as the hematologist speaking to a roomful of patients and caregivers, she vigorously asserted the need for WMers to be educated consumers and to fully understand what benefits will come from one’s participation in a trial if one opts to do so – the benefit to one’s self, to other patients, and to science. In the remainder of her talk, Dr.

Nichols outlined the questions to ask and whom to ask them of in order to determine the benefits she referred to. Every WMer who is considering joining a trial would do well to go over the points she raises in this very informative talk.

The remaining presentations on Saturday turned our attention to current research on WM when three leading lights in the WM research world, Drs. Ansell, Ghobrial, and Treon, stepped to the podium in that order.

“Pulling the Plug on Cancer Cell Communication” was the intriguing title of the talk by Dr. Stephen Ansell (Mayo Clinic). Dr. Ansell’s research zeroes in on the sheltered existence of the fragile WM cells in the bone marrow and especially on the process by which cancer cells communicate with the other cells that surround them. As that particular process works to keep the cancer cells alive, the focus of Dr. Ansell’s research efforts today is to disrupt that communication and cause the WM cells to die. Another research interest is to learn why the immune system “ignores” WM cells.



Dr. Stephen Ansell

To “pull the plug” Dr. Ansell’s research explores three possibilities. The first two consider cytokines. Cytokines are proteins essential to cancer cell communication and they are elevated in WM. One approach is to suppress their production. A second approach is to suppress the activity of specific cytokines. Finally a third approach is to find a way to block suppression of the immune system with antibodies. This simplified overview of Dr. Ansell’s work requires that you take a look at the slides of his talk to appreciate the very sophisticated biochemistry involved in this research.

Awards luncheon and Board report

Lunch on Saturday was the occasion for the IWMF Trustee Executive Board members to give reports about the strategic and financial status of the IWMF, patient and caregiver support, fundraising, and research funding initiatives that were successfully implemented in the past year and new initiatives planned for this year. Lots of great things are taking place from both a patient support and a research standpoint!

New members of the Ben Rude Heritage Society were also introduced by Laurie Rude-Betts at the luncheon, see page 19. Luncheon was also the occasion when the second Judith May Volunteer of the Year Award was presented, this year to Nicole Bastin of Waldenström France. Details on page 12.



Saturday afternoon program

After lunch, Dr. Irene Ghobrial delivered a rapid-fire overview of the “New Developments in WM Research” coming from the Kirsch Laboratory at DFCI, including a report on the preliminary results of her tissue bank study (which the IWFM has funded and in which about 500 WM’ers have participated so far – with additional folks at the Ed Forum registering to participate!).



Dr. Irene Ghobrial

research to include genomic studies of MGUS (monoclonal gammopathy of undetermined significance) and SWM (smoldering WM) – the precursor conditions to “full blown” WM – to assess if there is a way to determine who will and who won’t progress to WM.

One point of interest was Dr. Ghobrial’s coverage of the CXCR4 mutation in WM. Preliminary research indicates that the presence of the CXCR4 mutation predicts resistance to ibrutinib, RAD001, and CAL101 but not to carfilzomib and bortezomib. Further, WMers with extra-medullary manifestation of the disease have shown high levels of CXCR4.

Dr. Ghobrial revealed that she is expanding her



Dr. Steven Treon

and understanding the impact of this mutation now opens the door to developing treatments specifically for WM. The first example of such a targeted drug is ibrutinib (Imbruvica). While ibrutinib is proving to be an effective treatment for WM, we are still far from a cure. Dr. Treon expressed his confidence that further genomic study of WM will lead to other and more effective treatments.

The last speaker of the day was Dr. Steven Treon of DFCI who directed our attention to the “Advances in Management of WM Revealed by Whole Genome Sequencing” by pointing out that the older drugs used to treat WM were actually developed for other related diseases first and then used on WM patients. Whole genome sequencing of WM patients, however, has shown that the MYD88/L265P somatic mutation is very prevalent in WM,

You can hear more about the performance to date of Imbruvica and watch Dr. Treon field questions “live” from the Ed Forum by viewing the video of this presentation on the IWFM website.

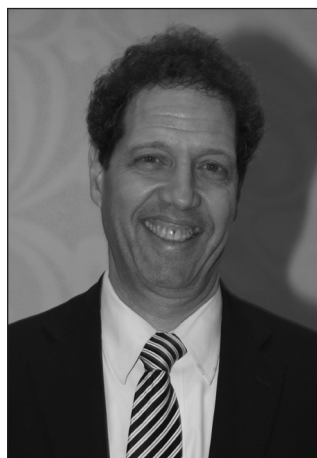
Breakout sessions

And if all of the above were not enough, the day ended with breakout sessions targeting the newly diagnosed, peripheral neuropathy, caregivers, cancer-associated fatigue, and yoga!

SUNDAY, MAY 18

Sunday morning

Sunday morning opened with Dr. Morie Gertz of Mayo Clinic, another luminary in the field of WM research, addressing “The Burning Questions About WM,” his response to a series



Dr. Morie Gertz

of questions and issues that plague us all. I’m sure you’ll find much that speaks to your own private concerns in Dr. Gertz’s remarks. As is his style, Dr. Gertz began with a bit of humor and continued to pepper his words with his unique sense of humor. You can see for yourself how your own particular “burning issues” were addressed and savor the flavor of Dr. Gertz’s peppered speech by viewing the video available on the IWFM website.

The closing event of Ed Forum 2014 was the now traditional interactive panel known as Ask the Doctor. Forum attendees are invited to write down in advance questions to the panel on index cards that are then reviewed by the moderator, Dr. Kyle, who selects the questions to put to the panel. It’s always



Ask the Doctor panel, Dr. Robert Kyle at the podium.



interesting to hear the differing perspectives of different doctors who all answer the very same question, but in different ways! Panel participants this year were Dr. Gwen Nichols, Dr. Morie Gertz, and Dr. Steven Treon. You can also enjoy their lively repartee (and occasional disagreements) in the video version on the IWMF website.

Sunday afternoon

Fifteen golfers got together on a beautiful Sunday afternoon at Rocky Point Golf Club in Tampa for a “Scramble for WM.” Boxed lunches were provided, and Sara McKinnie from the IWMF Office, who golfed in the event, made up some fun “goodie bags” for everyone. Best of all, the event raised money for a good cause, and the participants had a great time golfing and getting to know each other.



Golf scramble participants celebrated an afternoon of sport and camaraderie.

Final comments

Once the meeting was over, one could see groups of attendees gathering together for final goodbyes, trading e-mail addresses and phone numbers, and making plans to be sure to get together next year. By the end of the weekend, the Ed Forum has always proven to be an event that provides a wide variety of opportunities to enable one to better deal with WM: by gaining new information about treatment options, symptom management, and coping strategies from researchers and professionals (and from fellow patients and caregivers); by connecting one-on-one with leaders in WM research and treatment to address specific questions about your particular

disease circumstances; by getting a strengthened sense of how the IWMF can be of assistance to you in your times of need; by building long-term relationships with patients and caregivers who know exactly what you’re going through; and by learning from each other’s experiences.

Many thanks are due to the Ed Forum Committee Chair Sue Herms and Committee members Carl Harrington, Elena Malunis, Ron Yee, and Sara McKinnie, for all the time and effort involved, both months in advance and on the spot, to orchestrate such a great Ed Forum. And thanks to the IWMF Office staff and volunteers for terrific support.

Next year’s Ed Forum will be from May 1-3 in Dallas, Texas. Why not plan now on being there? I look forward to “secretly” seeing all of you there!

Postscript: Secret Wallie unmasked

The conclusion of another Ed Forum leaves us with one “burning question” yet unanswered: who *is* Secret Wallie? Over the years we have come to count on the anonymous bulletins coming directly from the Ed Forum front and posted nightly on IWMF-Talk to spread the special buzz that only an Ed Forum can generate. Speculation regarding the personality behind the familiar “nom de blog” has suggested several possibilities, and now it is time to “unmask” Secret

Wallie and give credit where it is due.



Trustee Pete DeNardis, aka Secret Wallie.

No, Secret Wallie is not the indefatigable Dr. Robert A. Kyle, as has often been suggested.

Yes, Secret Wallie is none other than Peter DeNardis, our versatile IWMF Trustee who wears the many hats of IWMF-Talk Manager, Webmaster of IWMF.com, Co-Chair Patient Database, Co-Chair IT Committee, Publications Committee member, and Ed Forum photographer.

As Secret Wallie puts his mask aside, let us raise a glass of red wine in thanks to Pete for all the many roles he plays so well as an IWMF super-volunteer.



DIAGNOSIS AND MANAGEMENT OF ANEMIA IN WALDENSTRÖM MACROGLOBULINEMIA

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

Introduction

Anemia, one of the cardinal findings in Waldenström macroglobulinemia, is present in over 80% of those patients who are not on “watch and wait.” In some instances, the severity of anemia is mild and does not require intervention, while in others it is the major reason for designating a patient as being symptomatic and requiring treatment of Waldenström macroglobulinemia.

What is anemia? Anemia represents a reduction in the oxygen-carrying capacity of the blood. The red blood cells provide oxygen to the tissues to enable them to “burn” the nutrients in food and so to generate energy. This “process of burning” cannot occur without oxygen: energy cannot be generated without the delivery of oxygen to tissues provided by red blood cells. As a consequence, a reduction in the number of red blood cells, which is referred to as anemia, is measured by a reduction in the red blood cell count (or by a lower hemoglobin level or a lower hematocrit level), resulting in the inability to deliver inhaled oxygen. Anemia will manifest as fatigue, apathy, and shortness of breath with exertion. Anemia can be identified in individuals as they develop pale skin (pallor) due to the decreased amount of circulating red blood cells.

In Waldenström macroglobulinemia, the most common cause of anemia is a direct reduction in red cell production in the bone marrow due to replacement by Waldenström cells. [Note: Dr. Gertz has famously compared WM in the bone marrow to “weeds in the garden” in several of his Ed Forum talks] In patients with Waldenström macroglobulinemia, the progressive growth of the Waldenström cells (lymphoplasmacytic lymphoma) replaces the normal red blood cell production in the bone marrow, leading to an inability to produce red cells. [“The weeds choke the garden plants.”] Impairment of red cell production usually will not occur until the percentage of bone marrow replacement with Waldenström exceeds 40%. Patients who are anemic but have a very small amount of lymphoma in their bone marrow (15% or less) should suspect that the cause of their anemia might be other than Waldenström.

Anemia that is symptomatic and significant (hemoglobin level <11 g/dL) is often the trigger to initiate therapy for Waldenström. Successful treatment of Waldenström is virtually always associated with a rise in the hemoglobin level because the increase in the hemoglobin level reflects the reduction of lymphoma involving the bone marrow. This “recovery of garden plants” (the good cells in the bone marrow) accomplished by “weed destruction” (reduction of the lymphoplasmacytic lymphoma cells) through effective

treatment, is the most common reason to treat Waldenström. Thus increased red blood cell counts and increased hemoglobin and hematocrit levels represent key outcome measures of successful therapy.

Are there other causes of anemia in Waldenström?

For Waldenström patients, as for everyone in the general population, there is a possibility of developing anemia unrelated to their Waldenström. Patients with Waldenström are not immune to other causes of anemia that may be related to blood loss, for example anemia generated by stomach ulcers that cause blood loss or by the development of colonic ulcers or polyps that bleed. Patients with Waldenström, like all cancer patients, should have a screening colonoscopy once every ten years as part of their preventive care. Situations where the anemia is out of proportion to the amount of Waldenström in the bone marrow should trigger a search for other causes of anemia. Screening stool specimens for the presence of blood is a very quick and simple way by which to identify blood loss anemia.

The group at Dana-Farber Cancer Institute has identified iron deficiency as an important cause of anemia in Waldenström. Iron is a key component of the hemoglobin molecule found in red blood cells. Iron deficiency does not require treatment of Waldenström but does require replacement of the missing iron to allow for the production of red blood cells. As part of the initial investigation of a patient with Waldenström, it is reasonable to require that screening iron studies be performed to exclude the possibility of unrecognized iron deficiency anemia. The most common tests used to diagnose iron deficiency anemia are the serum iron, total iron binding capacity, and serum ferritin levels. Improvements in the blood count, both hemoglobin and hematocrit, can occur with iron replacement. Taking an iron supplement by mouth may result in improvement; in some instances, however, oral iron replacement is not sufficient, and iron infusions are then given intravenously in order to replace the missing iron.

Rarely, patients with Waldenström macroglobulinemia can have cold agglutinin hemolytic anemia. This is a disorder where the IgM protein results in damage to the red blood cell. Damaged red blood cells are subsequently removed from the circulation in the liver and in the spleen. The mechanism is more complex than direct Waldenström involvement of the bone marrow, and thus the therapy is both more complex and often more frustrating. In many patients, high doses of cortisone or prednisone are required to manage the cold agglutinin hemolytic anemia. Treatment for such patients, however, is often the same as for patients with Waldenström

Diagnosis and Management of Anemia, cont. on page 35



NICOLE BASTIN: 2014 JUDITH A. MAY VOLUNTEER OF THE YEAR

BY JUDITH MAY, IWMF PRESIDENT EMERITA

It has been my honor to work with many committed and talented people who volunteered to help the IWMF over the years because they care about Waldenstrom patients and believe in the mission of the IWMF. Such volunteers dedicate long hours because they believe that patients who are assisted and supported by others will find it easier to shape their own futures in a positive manner.

In 2012 the IWMF Board established an award to annually recognize a single volunteer for their outstanding dedication to and support for Waldenstrom patients. Furthermore, the Board designated this award the Judith A. May Volunteer of the Year Award.

At the recent IWMF Educational Forum in Tampa, the Judith A. May Volunteer of the Year Award for 2014 was presented to Nicole Bastin of Le Blanc, France, for her efforts, spanning over nineteen years, to improve the lives of WM patients in France.

Nicole, in her humble way, will tell you that she was only continuing the work begun by her husband, Freddy Bastin. However, it was her knowledge drawn from her past careers that gave her a most appropriate background for helping to grow the Waldenstrom patient program in France.

Nicole began her career as a nurse in an academic hospital. When, some years later, she decided on a career change, she pursued and received both a Master's degree in human resources and a Ph.D. in management and organization. Her research during this time followed her interests in individual and collective decision-making in both for-profit and non-profit organizations and in the evaluation of public policies in the areas of health and employment. During these busy years she was also raising her young daughters.

When Freddy Bastin was diagnosed in 1995, Nicole was always by his side as he struggled with Waldenstrom's macroglobulinemia for eight years. Freddy himself was an activist who understood that he and all French Waldenstrom patients needed to educate themselves concerning this

disease. With her knowledge and skills, Nicole assisted him in the extensive work of translating all documents provided by the IWMF into French, establishing a lifeline program in France, and developing a French page on the IWMF website. Nicole and Freddy Bastin were, in Nicole's words, encouraged by Arnold Smokler and Ben Rude to move ahead with "improving knowledge of Waldenstrom's for the French-speaking patients and not allowing them to remain in isolation."

Following Freddy Bastin's death in 2003, Nicole was determined to continue the work her husband had started, and she worked to further expand the WM program in France. Nicole has continued to translate every new booklet published by the IWMF, to translate each *Torch* newsletter into French, to set up a French-speaking talklist, and to help expand the French-speaking WM patient association in welcoming all those outside of France who speak the French language.

For her years of work to educate and assist the Waldenstrom patients of France and all other francophone countries, we applaud Nicole and honor her for such dedication to Waldenstrom patients.



Nicole Bastin, recipient of the second Judith A. May Volunteer of the Year Award, is congratulated by Judith.

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 MEMORIAM: ANNE GREENE

BY JUDITH MAY, IWMF PRESIDENT EMERITA



Anne Greene

It is with great sorrow that we report the passing of Anne Greene who was a member of the first Board of Trustees, serving on the Board from 1998 to mid 2000. Anne died March 14, 2014, of complications from Waldenström's macroglobulinemia with which she had lived for seventeen years.

Born in San Diego in 1940, Anne pursued undergraduate studies at

Westminster College of London, the University of Grenoble, and the Monterey Institute of Foreign Studies. She received a Masters degree in Latin American Studies from The George Washington University, and in 1990 completed her Ph.D. in International Relations. Her career included teaching positions at the University of Indonesia, the United States

Naval Academy, a research position at Howard University, and a staff position on the Senate Intelligence Committee.

Anne was married in 1963 to Michael Peter Greene. Her work, and Michael's work, and their shared love of travel took them all over the world including a year in Peru, three years in Indonesia, and scuba diving trips almost everywhere. Other travels for work or pleasure took them to Haiti, the former Soviet Union, Latin America, Europe and Asia. Anne loved music and studied voice and guitar. She was a life-long learner, taking classes in subjects ranging from Chinese to flower arranging. Anne and Michael have two married daughters, Lesley and Diana, and Anne loved spending time with them, their husbands, and their four children.

Anne Greene is survived by her husband of fifty-one years, Michael Peter Greene of Lanham MD, by her daughters Lesley Greene and Diana Greene Foster, and by her grandchildren Anneke, Tanya, Noah, and Kaia. Long-time members of the IWMF remember Anne for her warmth, vitality, and gregarious personality.

The family asks that contributions be made to the IWMF in Anne's honor.

MICHEL HOUCHE MAY 1955 - JUNE 2014

BY FRANÇOIS SOULIÉ, TRUSTEE WALDENSTRÖM FRANCE



Michel Houche

It is with great sorrow that we inform you of the death of our friend Michel Houche, President of Waldenström France. Our entire organization is in mourning following the death of such an exceptional man. We address our deepest and most sincere condolences to Brigitte, his wife, who stood by him and supported him in all his endeavors, and to David and Martin, his dear children.

Few men have had such a rich and productive life. A nuclear chemist by profession, Michel worked at the nuclear plant of Marcoule, in the south of France, for thirty-two years. Among his colleagues he will be remembered for the uncompromising professionalism he showed in all circumstances.

Michel was also an outstanding sportsman. He played for his local amateur rugby team in southern France for twenty years, then for fourteen years he continued as a referee. He was a keen volleyball player and tennis player as well. As if this was not enough, he managed to assemble the largest collection of Coca-Cola bottles in the world – four thousand items, each different, and from different countries, some unique examples. He started by filling the various rooms of his flat in Avignon with Coca Cola memorabilia and then proceeded to open a museum dedicated to his passion, open to all free of charge.

Michel Houche was not only a man full of energy, he was also a generous man, always ready to help others, as attested by his three-year commitment to the French charity "Les Restos du Coeur," whose purpose is to feed the needy. For the last two years Michel was in charge of the Avignon branch.

Diagnosed with Waldenström disease in December 2006, he bravely put up with different treatments, first with

Michel Houche, cont. on page 14



chloraminophene in 2007, then with RFC in 2007-08. He also had surgery on his mitral valve in 2009. Finally, after being diagnosed with large cell lymphoma in January 2013, Michel went through six treatments of R-CHOP, followed by an autologous transplant. This was a very trying time for him from both a physical and a psychological point of view.

In 2008, spurred by his drive as an activist, Michel organized the very first French Waldenström patient meeting in his hometown of Avignon. The following year he organized the first patient-doctors meeting in Vienne, France. Other meetings followed each year, some in Paris, others in Vienne. Thanks to those meetings, French Waldenström patients were able to come in contact with the most renowned specialists in our country. On the occasion of the 2009 patient-doctor meeting, the French organization Waldenström France was created, and Michel naturally became its President and its untiring and efficacious leader.

As President, he immediately understood the necessity of creating an Internet site, in addition to our very useful talklist, to provide all Waldenström patients, wherever they are, the opportunity to find a place of comfort with pictures and personal stories as told by fellow sufferers, and also a well-documented library. On the Waldenström France site, viewers can see a map of France locating all members so as to allow for personalized exchanges within in the same area. It is thanks to Michel's determination that our organization can now benefit from such an irreplaceable tool.

And it is also thanks to Michel that some of us were given the opportunity to take part in a biological workshop put together by the organization "Tous Chercheurs" to help us better understand our illness.

Those of you who attended the IWWM workshops in Stockholm and in Venice or came to the first International IWMF Doctor-Patient Forum in London might have met him, and perhaps you had the opportunity to exchange a few words with this remarkable, open-minded man, always ready to communicate with others.

Michel was a kind-hearted man. He could make every one feel unique. He was extraordinarily enthusiastic, charismatic, and utterly funny. All of those who met him will remember his marvellous smile and his extraordinary feeling of empathy for others. He knew how to de-dramatize a situation and how to make fellow sufferers welcome, building a fireproof wall around them with his good humour and the warmth of his friendship.

In losing our President, we are losing not only a great organizer but also, and above all, a wonderful friend. From now on our orphaned organization will endeavour to take up the torch that Michel Houche lit and managed to keep alight for all those years.

Available on our Website: Booklet by Dr. Shirley D'Sa

Lymphoplasmacytic lymphoma and Waldenström's macroglobulinemia, WMUK Guides Number 2, written by Dr. Shirley D'Sa, hematologist/oncologist at University College Hospital, London, UK, is now available for downloading to PDF format at iwmf.com/iwmf-library/order-online.aspx As the booklet is written for WM patients and doctors in the UK, you will notice that the British English spelling of some words differs from American English. The drugs mentioned in the booklet are noted by their generic names and by their UK-specific trade names and may or may not be available in the UK or the US outside of the context of a clinical trial. The booklet is succinct and very well written, and we believe it is a great addition to our list of publications with the above caveats. Dr. D'Sa has approved our distribution to you.



INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

GERMANY

GERMAN WALDENSTROM MEETING

A meeting for German Waldenstrom patients and caregivers will take place on October 4 and 5 in Darmstadt, at the Hotel Commundo. The meeting is organized by the very active Leukaemia Patient Support Group RHEIN-MAIN (LHRM) under the leadership of Anita Waldmann, co-founder and chairwoman of LHRM. For information on the meeting and registration please go to the website www.@LHRM.de

Angelika Stippler reporting.

UNITED KINGDOM

WMUK NEWS

Coming in August: the Fifth International IWWM Doctor-Patient Forum in London will see 200 of us gathering for an excellent international speaker program. The London Forum will also witness the launch of an appeal for a UK WM clinical data registry being set up in memory of Rory Morrison, the BBC broadcaster who died a year ago. WMUK's new patron, broadcaster Charlotte Green, will lead the appeal.

A UK WM clinical data registry will allow doctors throughout the UK to enter data online in order to build up a picture of treatment and results. In the recent doctor survey, 100% of the responses supported the setting up of a registry. The cost will be an initial £25,000 plus £5,000 a year to professionally host. Taking a leaf out of IWWM's book, we have a generous foundation that will match pound for pound the first £5,000 donated, and there are already £15,000 in the registry fund, partly as a result of donations by Rory's fellow BBC colleagues and friends. All donors will be entered in our roll of honour.

At the Forum detailed results of both the doctor and patient surveys carried out by WMUK will also be released, as will details of the progress towards a WM tissue biobank being established at University College Hospital in 2015, hopefully as a result of joint IWWM/WMUK grant funding.

Roger Brown reporting.

CANADA

WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION CANADA: EDUCATION DAY IN VANCOUVER, BRITISH COLUMBIA

The WMFC Education Day was hosted by the WMFC and the British Columbia Cancer Agency (BCCA) in Vancouver at the Gordon and Leslie Diamond Family Theatre on April 5. About sixty participants from the BC mainland, Vancouver Island, Alberta, Washington State, and Oregon spent the day getting to know each other and gaining first class knowledge about WM.

The proceedings, moderated by WMFC President Arlene Hinchcliffe, included speakers from the Dana-Farber Cancer Institute (DFCI) in Boston and BCCA.

The first speaker, Zachary Hunter from DFCI, gave an update on the difficult subject of "Genomic Landscape of WM." As one patient summarized: "He made science accessible – a gentle, inclusive approach."



Drs. Joseph Connors, Laurie Sehn, and Alina Gerrie (from l. to r.) were among the speakers on Education Day. Photo thanks to Dr. Connors.

Dr. Joseph Connors is a member of the executive committee of the Hematology Site Group for the National Cancer Institute of Canada Clinical Trials Group, a Councilor of the American Society of Hematology, and is on the scientific advisory board of the Lymphoma Foundation Canada. Dr. Connors gave two informative talks: "Where WM Fits in the Spectrum of Lymphoid Cancers" as well as "Current Treatment Approaches to WM in British Columbia." Joe Connors is a wonderful presenter, and he answered many questions about treatment approaches and protocols. It was interesting to compare these with options available in the US.

Dr. Laurie Sehn spoke about "Transformations in WM." Many WM patients have expressed concern and fear about the issue of transformation, and Dr. Sehn was very helpful in putting it in proper perspective. Dr. Sehn is currently a Clinical Associate Professor with the BCCA and the University of British Columbia and has been a member of the Board of Directors for the Lymphoma Foundation of Canada since 2002, where she serves as the Director of Research Fellowships and is the Chair of the medical advisory board for the International Lymphoma Coalition.

After lunch, the topic "Stem Cell Transplants in WM" was addressed by Dr. Alina Gerrie. Dr. Gerrie is a hematologist and Clinical Assistant Professor at University of British Columbia in the Divisions of Hematology and Medical Oncology. She

International Scene, cont. on page 16



joined the Leukemia/Bone Marrow Transplant Program of British Columbia and the Lymphoma Tumor Group at the BCCA in January, 2013. Dr. Gerrie gave an excellent presentation outlining all the pros and cons of different types of transplants and when they may be warranted.

Joe Lewicki, a WM transplant patient, followed with a superb talk about his own experience with a donor transplant. A very personable and informed speaker, Joe captivated everyone's interest with his honest and transparent account of his journey before and after his allogeneic transplant. It was very helpful to have a patient's perspective.

A highlight of the day was Dr. Steven Treon, Director of the Bing Center at DFCI, who spoke about "New Treatment Options in WM." As always, Steve Treon continues to excite us with his interest in the search for better treatments, methods, and an eventual cure for WM. He left us wanting more!

The grand finale was an open interactive session with Drs. Treon and Connors. It was both fascinating and entertaining to hear the doctors discuss case histories and treatment approaches and receive feedback from each other. This session as well as the question and answer sessions proved to be a very effective strategy to connect with the conference speakers.

"This educational conference has been a very stimulating and informative experience offering ample opportunities for networking. Keep on doing what you are doing so well. Take comfort in this arena of life that you are making a huge difference."

(Michael, a forum participant)

Arlene Hinchcliffe, WMFC President, reporting.

AUSTRALIA

AUSTRALIAN ADVISORY GROUP

The Australian Advisory Group continues to focus on initiatives that enhance Australian WM best patient treatment and funding. Strong support in the areas of education, advocacy, and organisation from the IWWMF and the Leukaemia Foundation is much appreciated. Areas being addressed include:

- Organisation of suitable meetings and forums for WM patients and carers including WM patient support activities and the WMozzies website
- Active advocacy to widen the government funded pharmaceutical benefits scheme to include world-best WM treatments in Australia
- Facilitating financial donations to support WM research, scholarships, and fellowships
- Identification of WM specialist haematologists and hospitals experienced in treating our orphan disease

The Advisory Group has held two telephone conference meetings this year. Leukaemia Foundation leaders in Research & Advocacy and State Support attended. The current WMozzies members of the group are Peter Carr (Qld), Peter Marfleet (now WA), David Young (Northern NSW),

and Andrew Warden (Sydney). Intentions are to broaden the group membership to include other states and territories.

Patient educational meetings for WM Ozzies in Brisbane and Sydney are continuing with increased attendance. These are organised and hosted by the Leukaemia Foundation at their premises. Plans for similar meetings in Melbourne and Perth later this year are progressing. The Telephone Forums organised by the Leukaemia Foundation have attracted WMozzies city and country participants from all Eastern Australian states and Tasmania. Contact Tracey Dryden to participate: lymphoma@leukaemia.org.au

WMozzies website ownership has been transferred to WMozzies by its founder Colin Perrott (Congratulations to Colin on becoming the newest member of the IWWMF Research Committee). Web enhancements include direct links to IWWMF publications and details of the WMozzies patient support. This includes Australia-wide support services of the Leukaemia Foundation. Its teams of qualified health professionals are available at major haematology centres to visit WM Ozzies being treated or to follow up with them at home. Contact Tracey Dryden for more information about the Foundation's services or visit www.leukaemia.org.au/our-services

Advocacy by WMozzies is a priority. The focus is on the key aspect of funding access to new medicines for WM patient treatment. WMozzies attended the Cancer Drugs Alliance Stakeholder Forum held in March in Canberra. It included patient groups, clinicians, academics, politicians, bureaucrats, and the medicines industry. Key issues included:

- Adequacy of Australian system for providing access to cancer medicines
- Ways for the consumer voice be heard effectively with regard to access to cancer medicines
- Impact of the regulatory and reimbursement environments on clinical practice
- Valuation of cancer medicines
- Appropriate evidentiary requirements for cancer medicines

Working groups are now being formed around the five key priorities identified. WM Ozzies have volunteered for the working group for establishing a national chemotherapy registry. This dovetails in with the WMozzies CART-WHEEL data base project.

The **WMozzies CART-WHEEL data base project** is making good progress in providing specific research data on the effectiveness of WM treatments. The project is directed by CART-WHEEL Principal Investigator A/Professor Clare Scott, Walter & Eliza Hall Institute of Medical Research. The CART-WHEEL uses the BioGrid Australia secure research infrastructure and web-based platform that provides ethical access while protecting both privacy and intellectual property. The WMozzies pilot study has been successfully completed, confirming the validity of the CART-WHEEL database usage.



WARM GLOW GIVING

BY MICHAEL SESNOWITZ, VICE PRESIDENT FOR FUNDRAISING

The IWMF receives virtually all of its funding from donations, the vast majority of which come from individuals like you. Many of the member services made available by the IWMF are provided by volunteers. Why do people donate their time and treasure to a charitable organization like the IWMF?

In a recent Op Ed piece in The New York Times, Arthur Brooks argued that volunteering and donating increase happiness because they allow individuals to improve ‘self-efficacy,’ a term he defines as “one’s belief that one is capable of handling a situation and bringing about a desired outcome.” Brooks goes on to argue that “when people give their time or money to a cause they believe in, they become problem solvers.” And he believes that such people “... are happier than bystanders and victims of circumstance.” None of us chose to get WM, so we may be thought of as victims of circumstance, and our family and friends may be thought of as bystanders. But by donating our time and our money, we take charge of our situation and cease to be victims and bystanders.

Indeed, the *raison d’être* of the IWMF is to enable us to take charge of our disease by supporting research that can lead to better treatments and, possibly, a cure, and by providing knowledge and services to our entire community through the website, the annual Ed Forum, the *Torch*, support groups, the Lifeline, the Patient Database, and the numerous publications that have helped educate so many of us.

Who reads and approves the research proposals submitted to the IWMF? Expert volunteers on our Scientific Advisory and Research Committees. Who funds the approved research that is helping so many of us? Donors. Who creates and maintains the website? Volunteers. Who funds it? Donors. Who plans and executes the annual Educational Forum? Volunteers. Who helps fund it? Donors. Who writes and edits the *Torch*? Volunteers. Who funds its printing and distribution? Donors.

Who organizes and leads our support groups? Volunteers. Who staffs the Lifeline? Volunteers. Who creates and manages the Patient Database? Volunteers. Who funds it? Donors. Who writes and edits the educational pamphlets? Volunteers. Who funds their printing and distribution? Donors.

Consider how little was known about WM when Arnold Smokler founded the first WM support group in 1994. Because he and those who joined him did not want to remain victims of circumstance, our knowledge of WM has increased significantly and the foundation has been laid for finding better treatments and a cure. IWMF support for research has led to the development of reliable WM cell lines, a WM tissue bank, and a WM mouse model, all of which are being used to increase our knowledge of the disease. IWMF funds have also supported the whole genomic sequencing that led to the discovery of the mutations shared by most WMers. It is this research that has enabled the development of targeted therapies and has increased the likelihood of finding a cure. It is the services provided by the IWMF that have enabled us to understand and cope with our disease; it is the research that we have funded that has improved the quality and length of our lives.

Brooks’ arguments about happiness and giving are not mere assertions, but are supported by academic research. Survey data have consistently found that people who donate to charity report increased happiness. Researchers using experimental methods have found similar results. Giving that increases the donor’s happiness is referred to as **warm glow giving**. While such donors are certainly altruistic, they also receive an intangible benefit from giving, a warm glow, that increases their own welfare. This win-win situation helps explain why we have so many donors who are so generous with their time and their funds.

Warm Glow Giving, cont. on page 18

We Need Your Help

Approximately 14 percent of all giving in the United States comes from foundations, amounting to well over \$40 billion per year. While we have all heard of the large philanthropic foundations such as Ford, Gates, and Rockefeller, there are a large number of much smaller family foundations that support a wide variety of charities. Many of these smaller foundations do not accept unsolicited proposals. The easiest way to approach these foundations is through a member of the foundation’s board. This is where we need your help.

The IWMF has over 6,000 members. It is likely that some of our members either have contacts on foundation boards or know someone who does. If you fall in this category, you could help the IWMF raise funds for research and vital member services by providing an introduction to a member of the foundation’s board. If you know a board member of a foundation that supports medical research or the type of services we provide to our membership, please contact Lisa Abbott at 941-587-9786 or office@iwmf.com

Together, we can make a difference.



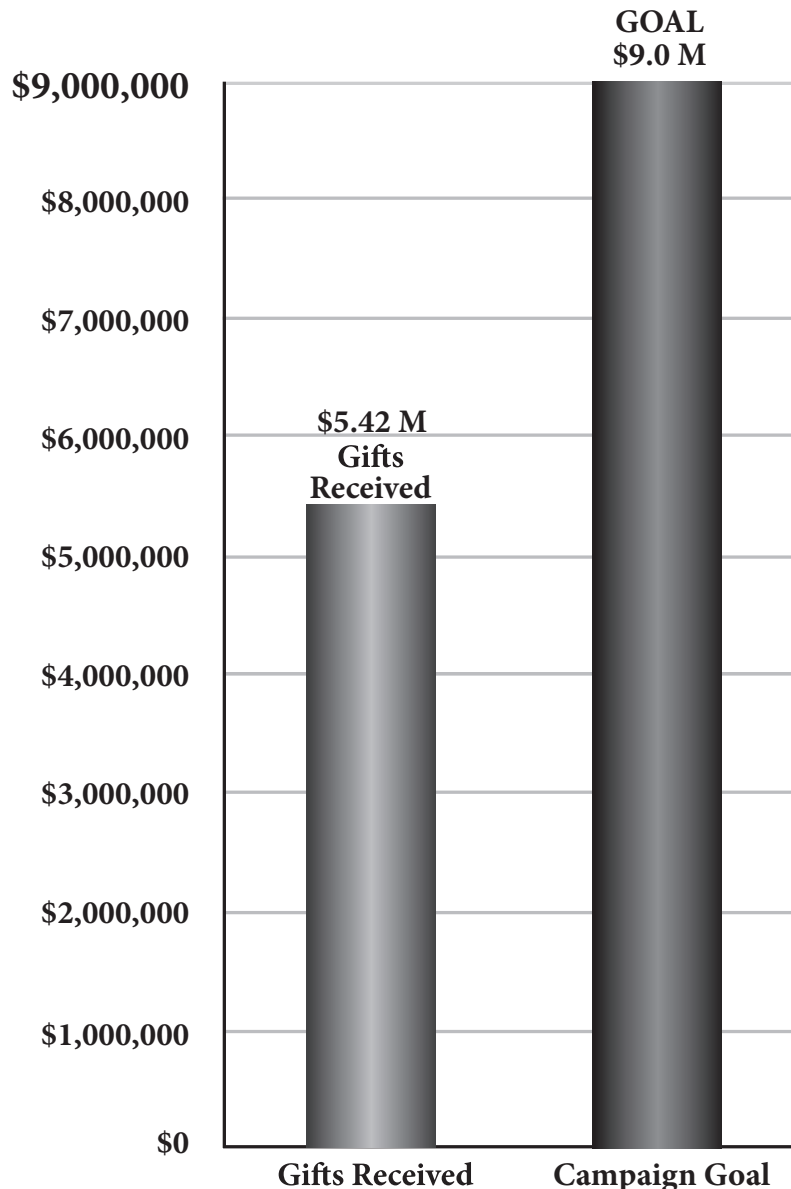
Some researchers have even used functional magnetic resonance imaging (fMRI) to demonstrate that the reward centers of the brain are activated by charitable giving, so there is also physiological evidence of the warm glow effect.

Over the years comments from donors have confirmed what the research has found. Time and again we have been told how fortunate donors have felt that they were able to contribute to the cause, expressing great satisfaction from seeing their funds help others while improving options for themselves.

Last year the IWMF received approximately \$1.3 million in donations from almost 2,200 donors and thousands of hours of volunteer time. These funds and volunteer time were used to

support ongoing and newly approved research projects and to provide continuing vital membership services. We thank you for making this possible through your generosity and hope that the warm glow effect increased the happiness of each and every one of you. We know that the donations supporting vital member services and research have certainly increased the welfare of our **entire WM community**, and hope that we can be even more successful in spreading happiness this year. Because ours is a very rare disease, both volunteer and financial support beyond our membership is very limited. So please consider joining other WMers with new or increased support in 2014 and ask your family and friends to join as well.

Imagine a Cure Campaign Progress Report as of April 30, 2014



The total amount for Gifts Received includes all gifts to the Member Services and Research Funds, pledges made over a five year period, and planned legacy gifts.



THE BEN RUDE HERITAGE SOCIETY GROWS

BY LAURIE RUDE-BETTS

At this year's Educational Forum in Tampa, twelve new members were inducted into the Ben Rude Heritage Society. In 2008, I was deeply moved to help establish the Ben Rude Heritage Society in honor of my late husband. Ben was the second IWMF President, and his leadership and legacy live on through this Society.

The twelve members inducted in 2014 made provisions for the IWMF either through bequests, gift annuities, trusts, insurance policies, or similarly planned gifts. With these gifts, the IWMF will ensure support for those affected by WM and will fund continued research in WM on behalf of the 1,500 patients who are newly diagnosed every year, as well as for veteran patients.

Currently we have 45 members in the Society including the 12 new inductees honored this year. In 2008, the Society started with 11 founding members who made legacy provisions of nearly 250 thousand dollars. In only six short years, the total value of bequests received as well as future provisions has grown to just over 3 million dollars.

In Tampa the following Society members were honored posthumously: Christina Conley from Scarborough, Maine; Jean Ellis from Royston, United Kingdom; and Alan Prestell from Cannes, France. Several inductees asked to remain anonymous.

New members Jack Baker from El Cajon, California, and Judith Sterling and her husband Leslie Wilson from Honolulu, Hawaii, were unable to join us at the Ed Forum this year. We were able to welcome three new members who were with us in Tampa – Roy Langhans, Dr. Robert Kyle, and Cynthia Ruhl.



Laurie Rude-Betts with new members of the Ben Rude Heritage Society, IWMF Treasurer Cynthia Ruhl and Trustee Dr. Robert Kyle.

Roy Langhans, from Cockeysville, Maryland, is a member of the *Imagine a Cure* Campaign advisory committee. Roy is retired from McCormick & Company, an American food company specializing in spices.

Dr. Kyle is from Rochester, Minnesota, and, as most of you know, has been involved in the IWMF since its inception. He currently serves as a member of the Board of the IWMF and the chairman of the IWMF Scientific Advisory Committee. Dr. Kyle and I are also the honorary co-chairs of the *Imagine a Cure* Campaign. For over sixty years Dr. Kyle has worked at the Mayo Clinic and is one of the world's leading authorities on Waldenström's macroglobulinemia.

Cynthia Ruhl is a CPA and principal in the firm Hull Ruhl & Moore in Redondo Beach, California. Cynthia serves as Treasurer for the IWMF Board.

We thank these donors and their families for their generous gifts and for showing their support for the Ben Rude Heritage Society!

You should know that this group reflects a cross section of our membership and has continued to grow in the past year. Those honored this year have provided approximately 1.25 million dollars in new provisions for the IWMF. All members have made legacy provisions assuming that there will continue to be a need for support for the newly diagnosed and their families and a need for additional research to identify improved treatments as we search for a cure for our disease.

Legacy provisions are an important part of the IWMF's future, and the legacy portion represents 20% of the *Imagine a Cure* campaign. If any of you are thinking about your personal estate planning, I hope you will consider including the IWMF as a beneficiary. If you would like more information about ways to leave a legacy gift, please contact the IWMF office or Dave Benson, the IWMF's Senior Development Officer. Dave can be reached at 952-837-9980 or dave@dbenson.com

Please remember how important you are to the IWMF as we are such a small family of rare cancer patients. Without your support we would not be able to provide the necessary educational resources to our members and our research needs would go unnoticed. Your planned gift to the *Imagine a Cure* Campaign ensures that your legacy and leadership, too, will live on through the Ben Rude Heritage Society of the IWMF.



MEDICAL NEWS ROUNDUP

BY SUE HERMS

New Clinical Trial to Open for Novel Anti-CD70 Antibody in WM – The Leukemia & Lymphoma Society and arGEN-X, a biopharmaceutical company focused on developing therapeutic antibodies for various cancers and autoimmune diseases, have entered into a partnership to fund a Phase II clinical study of ARGX-110 in patients with refractory WM. ARGX-110 is a novel anti-CD70 antibody that is being evaluated across a range of hematological and solid tumors in Europe. It works by blocking the growth of tumor cells, by killing tumor cells, and by activating a patient's immune system against the tumor. The new trial is expected to begin in the second half of 2014 and will be administered by the Bing Center at Dana-Farber Cancer Center.

Europe May Approve Subcutaneous Administration of Rituximab – A subcutaneous formulation of rituximab could soon be available in Europe. Rituximab is currently delivered by intravenous (IV) infusion, which takes approximately 2.5-3 hours, while the subcutaneous formulation can be delivered in approximately 5 minutes and will be available in ready-to-use fixed doses. The Committee for Medicinal Products for Human Use (CHMP) has recommended the subcutaneous formulation for approval by the European Commission. The recommendation was based on a Phase III study which compared 1400 mg subcutaneous rituximab with 375 mg/m² IV rituximab, each in combination with standard chemotherapy for patients with previously untreated follicular lymphoma. Subcutaneous administration-related reactions were primarily mild to moderate, and overall response rates were comparable between the two arms of the study. There are no immediate plans to market the subcutaneous formulation in the U.S.

Idelalisib Phase II Results Reported in Indolent Non-Hodgkin's Lymphoma – The *New England Journal of Medicine* reported a Phase II study of idelalisib, an oral PI3K delta inhibitor, in 125 patients with indolent non-Hodgkin's lymphoma, 10 of whom had lymphoplasmacytic lymphoma/WM. These patients either did not have a response to rituximab and an alkylating agent or had relapsed within 6 months after such treatment. Idelalisib was administered at 150 mg twice daily until disease progression or withdrawal from the study. The response rate was 57%, with 6% complete responses. The median time to a response was 1.9 months, the median duration of response was 12.5 months, and the median progression-free survival was 11 months. The most common adverse events of grade 3 or higher were neutropenia (reduced neutrophils), elevations in aminotransferase (a liver enzyme), diarrhea, and pneumonia.

British Study Looks at Hypogammaglobulinemia Following Rituximab Therapy – A retrospective review of hypogammaglobulinemia (lower than normal antibody

levels) after rituximab treatment was reported by the Royal Brompton Hospital in London. This multi-center London study looked at patients previously treated with rituximab who exhibited symptomatic or severe hypogammaglobulinemia and identified 19 of 114 post-rituximab patients with persistent hypogammaglobulinemia, with a mean IgG level of 3.42 g/L (normal 5.8-16.3 g/L). These patients had reduced or absent numbers of B-cells and reduced antibody levels to bacteria such as *Haemophilus influenza* type B, tetanus, and pneumococcus; these patients also failed to develop an immune response following vaccination. Nearly all of them ultimately required intravenous immunoglobulin (IVIg) replacement therapy. The mean interval from the last rituximab dose was 36 months.

Italian Study Evaluates Use of Subcutaneous Immunoglobulin Replacement Therapy – Padua University in Italy evaluated the use of subcutaneous immunoglobulin replacement therapy for hypogammaglobulinemia (lower than normal antibody levels) following treatment with anti-CD20 monoclonal antibodies in patients with lymphoproliferative disorders. Intravenous immunoglobulin (IVIg) has been a standard treatment for this condition, but this retrospective study compared intravenous vs. subcutaneous administration in 61 patients. The researchers noted that both were effective in replacing immunoglobulin deficiency; however, subcutaneous administration achieved higher IgG levels and a lower incidence of overall infection and the need for antibiotics. As expected, a lower number of adverse effects was registered with subcutaneous administration, with no serious adverse events.

Idera Presents Preclinical Data on IMO-8400 – Idera Pharmaceuticals presented preclinical data on its Toll-like receptor antagonist, IMO-8400, in the treatment of B-cell lymphomas, including WM, harboring the MYD88 L265P genetic mutation. The presentation at the 2014 American Association for Cancer Research (AACR) Annual Meeting discussed additional evidence that the mutation results in over-activation of TLR7 and TLR9 signaling and that blocking these TLRs with IMO-8400 leads to tumor cell death. Key downstream signaling pathways inhibited by the blocking action include IRAK-1, IRAK-4, BTK, STAT-3, Ik-Ba, and NF kappa-B. As reported in a previous column (April 2014 *Torch*), Idera has opened enrollment to a Phase I/II trial of IMO-8400 in patients with WM who are refractory to prior therapies.

Large Study Looks at Maintenance Rituximab Therapy in Follicular Lymphoma – A prospective observational study, published in *Cancer*, looked at the use of maintenance rituximab in 1,186 follicular lymphoma patients enrolled

Medical News Roundup, cont. on page 21



in the National LymphoCare Study who were diagnosed between 2004 and 2007. All patients achieved stable disease after induction therapy with rituximab, and 541 went on to receive rituximab maintenance therapy within 215 days after induction therapy. Median follow-up was 5.7 years. Overall, patients who underwent rituximab maintenance demonstrated extended progression-free survival and delayed time to next treatment; however, maintenance rituximab was not associated with improved overall survival.

Canadian Researchers Evaluate Larger Dosing of Subcutaneous Velcade – The Princess Margaret Cancer Centre in Toronto, Canada, evaluated a change in subcutaneous administration of Velcade (bortezomib) from the current 2 mL maximum volume for each injection site to 3 mL. In the 57 patients evaluated, skin reactions were noted in 42%, with all reactions being Grade 1 or Grade 2. Patients tolerated subcutaneous injections well, and only 4 patients were switched back to the intravenous route of administration. The study authors conclude that the higher dosage would reduce the number of injection sites required for most patients.

Results Provided for Phase I Trial of Pomalidomide in WM – The MD Anderson Cancer Center in Texas provided results of a Phase I study of pomalidomide in patients with relapsed/refractory WM. Pomalidomide is a newer generation IMiD in the same class as thalidomide and lenalidomide. All patients received daily oral pomalidomide at a 1 mg dose level, with dosage increases until the maximum tolerated dose was reached. The study took place between October 2010-January 2014, and 9 patients were treated. The maximum tolerated dose was established as 1 mg/day. Among the 8 evaluable patients, 2 had minor responses, 3 had stable disease, and 3 had progressive disease. Adverse events with higher dosing included neutropenia (reduced neutrophils), rash, fatigue, diarrhea, nausea, edema, headache, dizziness, mucositis (mouth sores), infections, peripheral neuropathy, constipation, itching, and night sweats. The researchers concluded that combinations with other effective agents should be studied, perhaps with abbreviated dosing schedules of pomalidomide.

Mayo Clinic Releases Outcome Data on Younger WM Patients – The Mayo Clinic in Rochester released outcome data on WM in young patients (less than or equal to 50 years of age). Such data are relatively sparse. During the period 2000-2013, 69 of 640 patients were in this category at diagnosis. Males constituted 65% of patients, and 9% had familial WM. The median follow-up was 8 years from diagnosis and 7.8

years from initial therapy. The 8-year overall survival was 84% from frontline therapy. Of the 18 deaths, only one was non-WM related. Of 67 patients treated, 65 (97%) received rituximab during their disease course. Twenty-five patients received nucleoside analog therapy, and 6 of those (24%) developed myelodysplasia or transformed lymphoma compared to 2% who received non-nucleoside analog-based therapy. These events occurred at a median of 7.6 years from nucleoside analog therapy, underscoring the avoidance of this type of therapy in the younger WM population. The use of autologous stem cell transplant appeared to be underutilized, occurring in only 8% of patients.

Researchers Look at Mechanisms of Ibrutinib Resistance in CLL Patients – An article in a recent issue of the *New England Journal of Medicine* discussed research that looked into mechanisms of acquired resistance to ibrutinib (Imbruvica) in chronic lymphocytic leukemia (CLL) patients. Ibrutinib targets the BTK signaling pathway in B-cells. Although only a small proportion of patients have relapsed on this therapy, an understanding of the resistance mechanisms is important. DNA sequencing was performed on samples obtained from patients at baseline and after relapse and identified one acquired mutation in BTK that changes the amino acid cysteine to serine and two additional acquired mutations in PLC γ 2, which is downstream from BTK; these mutations altered the functions of both molecules. This research was partially funded by the National Cancer Institute.

Multi-Center Study from Asia Reports on Vorinostat Treatment for Follicular Lymphoma – A Phase II trial from 18 centers in Japan, Hong Kong, Taiwan, and Korea looked at the use of vorinostat in relapsed/refractory follicular lymphoma. Patients received oral vorinostat at 200 mg twice daily for 14 days in a 21-day cycle until disease progression or unacceptable toxicity occurred. Vorinostat is a histone deacetylase inhibitor, which is thought to exhibit anti-tumor activity by up-regulating tumor suppression genes and inducing apoptosis (cell death). For the 39 evaluable patients with follicular lymphoma, the overall response rate was 49% and the median progression free survival was 20 months. Major toxicities were grade 3 and 4 thrombocytopenia (reduced platelets) and neutropenia (reduced neutrophils).

The author gratefully acknowledges the efforts of Peter DeNardis, Charles Schafer, John Paasch, and others in disseminating news of interest to the IWMMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.



FROM IWMF-TALK

BY JACOB WEINTRAUB M.D.

A brief lull during the IWMF Educational Forum interrupted the postings on IWMF-Talk while once again “Secret Wallie” provided daily updates about the Ed Forum, including not only details from the presentations but also the social and interactive portions of the meetings as well.

As always, old and new topics were discussed over the past months online. Ibrutinib/Imbruvica is an ongoing topic of interest to all as new results, experiences, and cautions arise. IVIG usage, sinus infections, Rituxan treatment and maintenance were all discussed once more. Useful links were posted to multiple articles about novel treatments, financial issues related to the cost of meds, and new statistics about treatments. On a happy note, we even welcomed a newborn, the baby of one of our young IWMF-Talk members. Many good wishes were sent to mother and child.

IMBRUVICA (IBRUTINIB)

As insurance coverage of Imbruvica evolves and becomes easier to secure, more users are reporting treatment and results from “off trial” uses. The discussion that follows addresses some of the new issues and relevant information reported by users.

Petechiae

Brian S reported that, after four weeks of treatment, side effects have become very manageable. His energy level is higher than it has been in years. However, he reports he has developed red spots that appear to be petechiae on his legs and arms. While he adds that the spots are not painful, he asks if anyone else had this in reaction to ibrutinib and what was the outcome.

Paul L commented that he has been on ibrutinib for six months and that petechiae come and go for no apparent reason. Paul does report having low platelets, at 30,000 to 50,000 (normal platelet count is above 150,000).

John P added that petechiae are not unique to ibrutinib treatment. When he was first diagnosed with WM, his platelet count was only 1,000, and he had a lot of petechiae, mainly on his feet. After treatment for his WM, John’s platelet count rose to above 250,000. He has had no petechiae since then.

Occasionally, however, he gets red splotches, but he feels these probably result from his bumping into something.

Food intake in relation to dosing

Scott K reported that he received an update from pharmacists at Pharmacyclics, the company that makes the med, recommending that a person have no food intake for two hours before and two hours after taking ibrutinib. Food apparently causes ibrutinib to go through the system much faster than it should, resulting in reduced absorption.

Paul L also asked about interference with liver enzymes, specifically CYP3A. It is known that grapefruit juice inhibits this enzyme and should be avoided. Paul asked about other foods that might have the same effect. As an example, Paul is drinking a lot of cranberry juice, and his ALT enzyme levels have increased significantly.

Colin P reported that he did a literature search and found mixed results. At least one study indicates that cranberry juice does elicit significant pharmacokinetic interactions with CYP3A. Therefore, it may be considered a potentially significant CYP3A inhibitor. Drinking cranberry juice should be done only with caution if a person is being treated with ibrutinib. However, it is still not clear if Paul’s elevation of ALT is related to cranberry juice interaction with the drug.

SINUS INFECTIONS

There was extensive discussion about sinus infections, their relation to WM, and their treatment.

Bonnie R wrote that she finished with BDR treatment (bendamustine-dexamethasone-Rituxan) in December 2012. The treatment was effective, but subsequently she has had pneumonia and a sinus infection. Her IgG was only 150, her IgA at 8. Bonnie started IVIG and received multiple antibiotics, but the sinus infections continued. Finally a CT scan showed her sinuses were totally blocked. Her ENT specialist believes that the blockage causes her persistent infections. Bonnie had sinus surgery recently and so far is doing very well and is continuing IVIG. She feels this may be the answer for many people with sinus infections.

From IWMF-Talk, cont. on page 23

HOW TO JOIN IWMF-TALK

Here are two ways to join:

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

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

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



Dave B reported a similar problem. He has had three months of continuous sinus infections, and antibiotics also have proved unsuccessful. His ENT is recommending a new procedure, a balloon sinuplasty, to increase the size of nasal passages and asked if Dave knows of anyone else with WM who has had this procedure. The doctor offered the opinion that patients with WM appear to be particularly susceptible to sinus infections.

Bob K wrote of his experience of using the NeilMed Sinus Rinse with good success for temporary relief.

Diana C also endorsed use of the NeilMed Sinus Rinse, but added that she has been prescribed clindamycin rinses. The med is mixed with saline by the pharmacist and has proven to be exceptionally beneficial for her. She is able to avoid oral antibiotics but has been receiving IVIG.

Pat G has had repeated sinus infections, too. Her ENT did a swab and documented that this was not a bacterial infection. Pat is taking Flonase Nasal Spray, Sudafed, and Zyrtec and will soon be taking another antihistamine. She wondered if a change in climate would be beneficial, someplace where the allergens are absent or at least different from the Southwest, where she lives.

Dr. Tom Hoffmann observed that there appears to be an increasing number of sinus infections reported on IWMF-Talk. Because IgG and IgA levels tend to decrease in people who receive treatment with Rituxan, Dr. Tom raised the question of the IgG and IgA level in people on Rituxan maintenance versus people not on maintenance and wondered if people on Rituxan maintenance have more sinus infections than people not on maintenance.

Gerald W responded by citing an article by Dr. Steven Treon of Dana-Farber. In this study the mean level of IgA was 10 mg/dl lower in Rituxan maintenance patients and the mean level of IgG 110 mg/dl lower in Rituxan maintenance patients than in non-maintenance patients. The occurrence of sinus infections in Rituxan maintenance patients was twice as high as in non-maintenance patients (15.1% versus 7.4%).

However, **Liane C** suggested that there must be more than just low IgA and IgG contributing to sinus infections. Liane had an autologous stem cell transplant some years ago, and she has ongoing low IgG with normal IgA. But she has never had a sinus infection – neither prior to, during, or after her bouts of chemo for her stem cell transplant. She thinks there may be other pre-existing conditions, for example sinus drainage problems, that go along with the lower immunoglobulin levels and sinus infections.

FOOT AND LEG CRAMPS

Leg cramps are a common problem frequently discussed on IWMF-Talk. Many people have sought medical opinions, and many have their own remedies that work well.

Sue B reported that she has some neuropathy in her left foot – no pain, just numbness. However, she has been getting very painful cramps in her left calf and asked if this could be related to her neuropathy. She has a normal potassium level and an IgM of 80.

Hank S replied that his oncologist indicated Hank's cramps were related to his neuropathy. Hank has found that drinking a lot of water and/or herbal tea before bed gives him relief. He has also obtained relief by drinking dill pickle juice, then more water. To date, no one else has reported the pickle juice cure.

In the past, quinine tablets were suggested as a remedy to leg cramps, but many reported that quinine is no longer available, owing to a safety issue.

Betty M also suffers from severe leg cramping, although it tends to subside after she receives treatment for her WM. Betty has used Schweppes tonic water, which reportedly contains some quinine, at the suggestion of Dr. Treon. She has also found that magnesium helps and that keeping hydrated is essential. During the night sometimes all she can do is walk until the cramps subside. Betty added that she doesn't drink much water but does drink a lot of coffee and tea. While this habit may contribute to dehydration due to the caffeine, she has been told that all fluids can help. She will soon be starting a new exercise program that includes leg and calf stretching, and she is hoping that will help reduce the cramps.

Dr. Tom Hoffmann suggested an old remedy, recommended many times in the past. He suggested placing a bar of soap in a sock and putting that between the sheets at the end of the bed.

IN REMEMBRANCE

Finally there were some sad notes, as news of the passing of WM patients reached our ears via IWMF-Talk and other venues.

Jeff Atlin was a long-term participant in IWMF-Talk whose death was reported on March 13 by our list manager, Pete DeNardis. Jeff's original diagnosis of WM was in May 1998, at the age of 49. A long time volunteer for the IWMF and WMFC in Canada, Jeff was a frequent contributor to this forum. I remember one of his early posts as he registered for and participated in an early clinical trial. His words were informative and humorous. Subsequent posts included his more recent stem cell transplant, carefully explaining and re-explaining his past treatments and new diagnosis of acute myeloid leukemia (AML).

Jeff's obituary was included in Pete's notice and can be found in the archives. It is very moving to read about Jeff's bold outlook in the face of his disease. His death is a great loss to the WM community.



COOKS' HAPPY HOUR

BY PENNI WISNER

Ahhhhhh, so. Finally, summer. Time for salad. In California, salad time lasts year round, but I won't crow about that too loudly. Meanwhile, I want to discuss salad dressing with you. Again. Do you remember we had a meeting about vinaigrette some time ago?

Lately, I have enjoyed some spectacular salads at local restaurants. Always my response is the same: How do they make it? New dressings can take your cooking (just because it is cold does not mean it's not cooking) to a new level and make those old basics – lettuce, radishes, cucumbers, carrots, etc. – interesting to eat again. Even if your appetite flags in the heat.

One salad was a bowl of cubed cucumbers in thick yogurt flavored with toasted sunflower seed butter, lemon juice, olive oil, salt, and pepper. The cucumbers were garnished with a few leaves of purslane (Do not weed it out of your garden, eat it instead.) and black sesame seeds. I've made a version with tahini instead of the sunflower seed butter and it was very good. Buying or making "butters" out of nuts and seeds other than the usual peanut and sesame is also a good, easy idea for adding different flavors and nutrition to meals. First toast the nuts and seeds until light brown and aromatic – or buy them pre-toasted and unsalted from stores with rapid turnover so you can be sure the nuts and seeds are fresh. Toasted nuts and seeds go rancid easily, especially in the heat. You could even make a "house" butter by making a blend of nuts and seeds that you particularly like.

A favorite dressing of mine is carrot-miso dressing, an orange creamsicle-colored sauce I adapted from Mark Bittman of The New York Times. In concept, I doubted its ability to sauce lettuce salads, but it does, wonderfully, and my family loves it (even he who looks askance at anything he doesn't recognize as "normal"). It's also great as a dip for raw vegetables and the color is so pretty and summery.

Cut a large, sweet carrot into chunks and microwave it until tender. Put it in a blender or food processor (but the blender gives a smoother result) with four, fat garlic cloves, a big

piece of peeled ginger (2 ounces is what I use, but I love ginger), 8 ounces white or yellow miso (white is milder in flavor), 8 ounces organic rice vinegar, 8 ounces water, and 8 to 10 ounces organic canola oil. Puree until smooth and taste for seasoning and balance. You may want to add a little lemon juice or a teaspoon of maple syrup. This recipe makes a lot and can certainly be cut in half but, if you pour it into a clean, glass, lidded jar, it keeps a good while in the refrigerator.

Here is my newest discovery, a vegan tahini green goddess dressing, learned from San Francisco vegan chef Alyssa Cox. I have learned a lot from her including her raw kale salad that I demonstrate at the UCSF Cancer Survivors Retreat twice a year. (Have you noticed that nearly every restaurant with salads on the menu includes one of raw kale?) One day, if I can figure out how it fits into the "healthy" category, I will give you her recipe for vegan brownies iced in a thick layer of chocolate-coconut ganache. (Sorry to be such a tease, could not resist.) This bright green dressing tastes fresh and vibrant. It can be used as a salad dressing, as a dip, as a sauce on vegetables, and even – if you eat them – on fish and poultry. You will need to adjust the final balance based on your palate and your ingredients. For instance, if you use Meyer lemon, you will need more vinegar and you might omit the honey.

In a blender or food processor, put 2 ounces (about 1/4 to 1/3 cup) tahini; 1 clove garlic; 1 1/2 packed cups mixed fresh herbs such as basil, dill, cilantro, parsley, chives, mint, tarragon, scallions; the juice and zest of 1 lemon; 1 1/2 to 2 ounces (about 1/4 cup) extra-virgin olive oil; about 1 ounce (about 2 tablespoons) apple cider vinegar; 1 to 2 teaspoons honey; 2 teaspoons white miso; about 1 teaspoon wheat-free soy or tamari (Don't worry about the gluten-free bit unless you try to avoid gluten. And, please!, read the ingredients of soy sauce and tamari. Not all tamari is gluten-free despite what you hear and read. Tamari refers to a robust style of soy sauce.); and sea salt and fresh pepper to taste. Blend until the sauce is as smooth as possible. You will probably need to add 2 to 3 ounces (about 1/4 cup) hot water to facilitate blending.

Our motto: Eat Well to Stay Well

IWMF Booklet Update: *Basic Immunology* Available!

The IWMF booklet, *Basic Immunology in Waldenstrom's Macroglobulinemia*, was revised by Dr. Guy Sherwood, MD, just prior to the 2014 Ed Forum in Tampa and includes information to help you better understand the promising new research into the genetics of WM. If you did not get a copy of this booklet at the Ed Forum, you can download it quickly on the IWMF website at www.iwmf.com/iwmf-library/order-online.aspx or contact our Business Office in Sarasota at 941-927-4963.



IN THE TORCHLIGHT

BY SARAH GARDNER

Once more our Torchlight spots another jazz musician of note – New York City’s Herb Gardner. Daughter Sarah Gardner wrote to report the strategy she employed to keep her father on track with his treatment at DFCI in Boston. Following Herb Gardner’s diagnosis of Waldenström’s macroglobulinemia, the need for treatment came in a rather dramatic and alarming manner when he collapsed just before a performance of Red Molly, the band comprised of three of the four Gardner daughters. Treatment was required, but the patient was resistant. Here Sarah Gardner describes in her own words the ploy that proved successful for both father and daughter. Sarah also reports that, with old contacts renewed in the Boston area, Herb today is performing in expanded venues, including both New York and Boston.

When Jazz musician Herb Gardner (“Pops”) was diagnosed with WM, his daughter Sarah begged him to get treatment at the Dana-Farber Cancer Institute in Boston. But Pops was



Herb Gardner surrounded by members of the Red Molly band: Laurie MacAllister, Abbie Gardner, Molly Venter. Photo by Sarah Gardner.

still playing gigs all over Manhattan, leading big bands in jazz clubs in and around the tri-state area. Whatever spare moments when he wasn’t performing were spent writing big band arrangements for other performers. He had no intention of stopping his music to spend any time in treatment. Daughter Sarah, a busy working mom in Norwood, MA, realized she needed a way that would require his music skills and combine her career at the same time, while getting him to Dana-Farber. She asked him to write arrangements and play piano and trombone on her new CD. Their collaboration, *Jazz Pour Le Bebes* (released May 1) is an authentic collection of Dixieland jazz for grandparents to enjoy with their grandchildren. If you have ever danced with a child, you know the boundless joy this type of music brings. And it brought everyone joy!

During the recording sessions (and treatment), Herb’s health took a huge turn for the better. We are convinced the project kept him coming and going through treatment! It was, quite literally, good for his blood. Herb grew up in Winchester, MA and graduated from Harvard. We brought his long-time New England jazz friends in on the project: Ted Casher (clarinet, sax), Bo Winiker (trumpet) and Bill Winiker (drums). Pops still plays gigs in NYC, but now performs in the Boston area too!

More about Herb at herb-gardner.com where you’ll meet an accomplished jazzman with a great sense of humor. *Jazz Pour Le Bebes*: listen at cdbaby.com

In the Torchlight is a column for sharing the personal stories of Wallies of all ages to illustrate spirit and strength in the face of adversity. Our pages are full of stories of awards, accomplishments, successful treatments, new adventures, strength of character. Won’t you share yours with the Torch? Let us hear from you at: ariginos@me.com

Run with Ryan: Support IWMF Research Fund

Ryan Scofield, a young patient from the Chicago area, announced that he would run in the Chicago Marathon along with four team runners in October. Their efforts will support the IWMF Research Fund; our Foundation is now registered with the Bank of America Chicago Marathon. If you would like to support Ryan and the IWMF, go to the iwmf.com website and click on the left hand column “Giving” link, and then “Bank of America Chicago Marathon.” Ryan’s personal story is also on this web link.



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 29-30.

CALIFORNIA

Sacramento and Bay Area

The group met at the end of July at the Kaiser Foundation Hospital in Vallejo. Participants, eager to hear about the May IWMF Educational Forum in Tampa, shared potluck refreshments and had a chance to discuss their personal experiences with WM and ask the group for insights.

COLORADO

On April 12, a beautiful spring day in Denver, the WM community participated in the one-day Rocky Mountain Blood Cancer Conference of the Leukemia & Lymphoma Society (LLS). A separate afternoon breakout for WMers featured Dr. Edward Libby. Dr. Libby is from the University of Washington and the Fred Hutchinson Cancer Research Center in Seattle. His presentation covered the history and diagnosis of Waldenstrom's, how it compares to other blood cancers, its symptoms, treatments, and prognosis for patients. Thirty-three attended the session and had lots of great questions throughout the presentation.

The rest of the day included excellent speakers on various cancer topics. Each attendee participated in three sessions and heard the keynote speaker, Pat Williams of the Orlando Magic (a multiple myeloma and stem cell transplant survivor). Dr. Lou DeGennaro, CEO of the LLS, was the featured speaker during the fabulous lunch. Dr. DeGennaro discussed LLS research successes and the need for further funding. It was a wonderful day and free to all! What a great partnership between the IWMF and the LLS!



Bill Bass and Cindy Furst at the IWMF table during the very successful one-day Rocky Mountain Blood Cancer Conference of the Leukemia & Lymphoma Society.



Members of the Connecticut support group at their April meeting. Co-leader Bob Hammond is in the back row, third from left, and co-leader Gail Arcari is seated, front row left.

CONNECTICUT

Eleven WMers, five spouses, and one daughter gathered on an April Saturday at Covenant Village of Cromwell in the center of the state. Attendees shared their stories of ups and downs with WM. One person said that he has been eating food the way it comes from nature: no processed foods. Another said alpha lipoic acid, a supplement, had staved off early signs of neuropathy. The whole group watched the 2013 IWMF Educational Forum DVD of Dr. Mary Hardy talking about integrative and complementary medicine. Finally, some participants continued getting acquainted over dinner at Ruby Tuesdays. **Francoise Lampe** is stepping down after eight years as co-leader. It is for a joyful reason. Francoise has had a complete response following an allogeneic stem cell transplant. Her leadership has been much appreciated, and she will be missed. **Bob Hammond** continues as co-

leader with **Gail Arcari**. Gail was diagnosed with WM in 2012 and is on "watch and wait." Unable to travel the distance to the usual location of the support group in the southwest of the state, she decided to host the group at her retirement community, Covenant Village of Cromwell, in the middle of the state. Gail has lived in Connecticut most of her life, attending Connecticut College for Women where she majored in zoology, followed by



Gail Arcari, new co-leader of the Connecticut support group.

Support Group News, cont. on page 27



training as a medical technologist, and then working in research. She took time to raise her wonderful family of three children, earned a Masters degree in education, and became a chronobiologist to study the timing inherent in living things, such as circadian rhythms. Leading an active life in retirement, Gail attends exercise class, walks a half hour every day, and has very little sugar or gluten in her diet.

ILLINOIS

Chicago Area and SE Wisconsin

A near-record number of attendees (70 including 14 “first-timer” families) turned out in April to hear Dr. Shuo Ma, M.D., Ph.D., of Northwestern University and the Robert H. Lurie Comprehensive Cancer Center discuss ibrutinib and other new treatments. Many commented that Dr. Ma’s presentation demonstrated just the right balance of technical and practical information. Summer plans are for the annual picnic on August 9 focusing on fellowship. The host will be a new member living in St. Charles. It is always nice to have air conditioning available for those hot August afternoons in Chicago.

INDIANA

The LLS hosted the group meeting at its new office in June. The Society also provided the all-important breakfast snacks and coffee for the attendees, including two new WM patients and their support people. The meeting opened with introductions and sharing interspersed with questions and discussions along the way. Co-leader **Gayle Backmeyer** gave a report of the IWMF Educational Forum in Tampa. One member talked about a book he had read called *The Depression Cure: The 6-Step Program to Beat Depression without Drugs* by Stephen S. Ilardi, Ph.D. People were very interested in the idea of using diet, exercise, and supplements to combat depression. The topic provoked a lively discussion about depression and its treatment. It was acknowledged that having cancer in and of itself can be a situational cause of depression. Plans are to meet again in October and a save-the-date announcement will be sent in the early summer.

NEW YORK

New York City

The New York Metro-Area support group met May 4, a spring Sunday so perfectly beautiful that it might have kept members away. Nevertheless, a large group of veterans and newbies convened for our typically lively and encouraging discussion about how no one ever wants to be a member of this group, and how, at the same time, there has never been a better time to join it! Many follow-up e-mails from attendees said how good it was to get together and how much value and stress-reduction result from participating. The July meeting, in conjunction with the LLS, featured a nutritionist with oncology experience. Her talk addressed how to adapt our food habits and preferences so we can become as healthy and fit as possible.

Rochester, Western and Central NY

The Rochester group is nearly inactive at this time. One new member has joined the small group in the last year. And now the group is smaller as one beloved member recently passed away. She had joined in 2001 and had needed repeated chemotherapy treatments with various drugs. Even though her body was weakened by the chemotherapy, you would not have known it. At the last group luncheon, she arrived full of vigor and glad to be with us. Her passing shocked and saddened us all. Her death attributed to WM but to a gradual weakening of her bodily systems due to chemotherapy. She will be greatly missed. The remaining members of the group seem to be well and prospering.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

The surprise of an 80°F day after an extremely long, cold winter sent everyone from the living room out onto the back porch of **Marcia and Glenn Klepac’s** home. Members enjoyed each other’s company and the sunshine on the exceptionally warm spring day. All updated their WM journeys over the winter. Two members joined the growing number of WMers on ibrutinib and were delighted to report an improvement in energy and quality of life. Much discussion centered around the mystery of how someone with a very minor increase in IgM can have pronounced symptoms while another with much higher IgM levels can remain symptom-free. The group illustrates the individuality of WM! Marcia reviewed two recent articles from the Bing Center at Dana-Farber. These described MYD88 and CXCR4 gene mutations in WM patients and testing for MYD88 with a blood sample. As always, delicious culinary contributions from members concluded the meeting and fueled further conversation.

OREGON/SOUTHWEST WASHINGTON

The Oregon/SW Washington IWMF Support Group held its regular quarterly meeting on Saturday, July 26, in Lake Oswego. About 20 WM patients and their caregivers met to hear Jules J. Auger speak on “Living With Cancer: Vulnerability and Gratitude.” Dr. Auger is a psychotherapist in the Portland area and also a WM patient since 1998. He is licensed by the State of Oregon as a Marriage and Family Therapist and is also a Diplomate (Retired) in the American Association of Pastoral Counselors. Dr. Auger began with his own story but quickly moved to some of the issues that having such a disease raises after diagnosis, treatment and stabilization. He talked of the realities of fear, learning to trust our bodies again, coping with compromised immune systems, and the ongoing reality of cancer’s potential return. Dr. Auger discussed how the trauma of cancer affects not only the patient but partners and family members as well. And then he outlined some of the issues for caregivers, such as feelings of helplessness as they see their loved one suffer, and the fatigue associated with dealing with the constant presence

Support Group News, cont. on page 28



of cancer. After all this, Dr. Auger raised the importance of gratitude for cancer patients: being thankful for medical care and treatments, for research and progress in understanding the various cancers, for support groups and ongoing caregiving by so many. An interesting and lively discussion followed with many taking part. Speaking of gratitude, the group is particularly grateful for generous support of the LLS and especially for **Sue Sumpter**, the Northwest LLS Patient Coordinator, who has recently retired. Sue and **Joan Berglund** were instrumental in getting the WM support group started about seven years ago. Sue has continued to be a supporter ever since. The group meets quarterly, on the last Saturday of the third month of the quarter, from 12 noon to 2 pm. The next meeting will be October 25, 2014. Meetings are at the Fairfield Inn and Suites, 6100 SW Meadows Road, Lake Oswego, Oregon. Lunch is provided.

PENNSYLVANIA

Philadelphia

After thirteen years, the group has a new meeting space in Bryn Mawr Hospital. Very happily, it turned out to be a beautiful, bright, comfortable room conveniently located on the first floor near the hospital entrance and parking! The June meeting was well attended. **Roy Langhans** and **Kathy Chapman** reported on their time at this year's IWMF Educational Forum in Tampa. This generated lots of enthusiastic discussion, and the two hours went by all too quickly. Two new members joined the regulars, as did several members who had not been present in some time. Unfortunately, hospital rules do not permit canine visitors in our new space, with the exception of therapy dogs. At first we thought that our group's mascot, the Pindzolas' little white dog, Heidi, would be able to qualify and continue to attend our support group meetings. But Heidi flunked her therapy dog training and was unable to attend. What she lacks in obedience she makes up in charm, but the hospital requires a certificate! Fruit, dip, and veggie chips rounded out the great meeting.

TENNESSEE

W. Tennessee, E. Arkansas, N. Mississippi

The Memphis area support group has already had a busy 2014 with meetings in March and June. The June meeting featured a lively presentation and discussion with Jodie Greear, R.D., certified specialist in oncology nutrition with Baptist Cancer Center in Memphis. Jodie answered questions sent to her before the meeting. Her numerous handouts covered nutrition suggestions and ideas for patients in and between treatments. The group continues to grow and expand geographically, with two new members attending in June. They traveled about 30 miles to join the group. More than a dozen patients from three states gather on a regular basis at the meetings.

VIRGINIA

Ms. Lu Kleppinger, a WM patient, is starting a new IWMF support group for northern Virginia. In cooperation with **Marcia Klepac**, IWMF Trustee, the first meeting will be a forum entitled "Familial Waldenstrom and MGUS: Your Questions Answered" featuring Mary L. McMaster, National Institutes of Health, National Cancer Institute, Senior Clinical Specialist, on Saturday, October 11, 2014. Lu's career in Washington D.C. included twenty-one years of service as director of conferences at The George Washington University where she collaborated with eight schools and organizations including the White House, the Department of Defense, the Smithsonian Institution, embassies, and others. Her last five years were spent planning occasions on behalf of the university president and his wife at their residence.



Lu Kleppinger, leader of the newly established northern Virginia support group.

Lu has served as a volunteer at INOVA Fairfax Hospital visiting patients with a therapy dog, the National Symphony Orchestra, National Museum of Women in the Arts, and assisting with Navy memorial services at Arlington National Cemetery. Her B.A. and M.A.Ed. in counseling are from Washington University in St. Louis.

WASHINGTON D.C. METROPOLITAN AREA

The main topic of conversation at the June meeting revolved around the recent IWMF Ed Forum. Eleven members joined the excellent discussion led by **Bonnie Beckett**, who had attended and taken great notes. Other attendees actively contributed by reporting some of their treatment experiences. Four meetings are scheduled annually. Future 2014 meeting dates are September 14 and November 30, all to be held at Holy Cross Hospital in Silver Spring, MD, Education Room 3, from 2:30 pm to about 4 pm.



Members of the Washington DC area support group at their June meeting, group leader Marilyn Bandel front row, second on the left.



IWMF SUPPORT GROUP CHAPTER LISTING

ALABAMA

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

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

ARIZONA

Phoenix

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

Jim Bushey
602-751-2463
bushman1948@gmail.com

ARKANSAS

Eastern

Bill Paul
901-767-6630
Billpaultax@gmail.com

CALIFORNIA

Monterey

(May - October)
Sandy Skillicorn
831-277-5274
sandyskillicorn@gmail.com

Southern California

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

Sid Bursten
949-226-7359
sid@sid-bursten.com

Sacramento/

San Francisco Bay Area

Alyce & Terry Rossow
925-447-8881
Rossow@ieee.org

COLORADO

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

Cindy Furst
970-227-4686
cindyfurst@gmail.com

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

CONNECTICUT

Gail Arcari
860-632-7032
gailarcari@att.net

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

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

DELAWARE

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

FLORIDA

Gainesville Area

Harriett Pawliger
Susan Boulet
352-331-7340
352-219-5674 cell
harpaw@aol.com
sjboulet@cox.net

Ft. Lauderdale Area

Charlie Koch
954-476-8726
charlie1030@bellsouth.net

Florida Keys

Regional Contact: Joel Pollack
305-852-8575
yoelpp@yahoo.com

Southwest Florida

Regional Contact: Joe Gallo
941-493-1809
galljocon@verizon.net

Tampa

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

Tampa Bay Area

Regional Contact: Bill Heyser
813-610-1211
bill.heyser@raymondjames.com

GEORGIA

Atlanta

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

HAWAII

(November-April)

Sandy Skillicorn
808-891-2882
sandyskillicorn@gmail.com

IDAHO

Eastern

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

Western

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

ILLINOIS

Chicago

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

INDIANA

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

KANSAS

Eastern

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

KENTUCKY

Marion Petry
bearpaw@earthlink.net
937-438-8850

LOUISIANA

New Orleans

Mindy Caplan
504-309-2247
mindycap@yahoo.com

MARYLAND

Marilyn Bandel
410-489-7875
ambandel@verizon.net

MASSACHUSETTS

Boston

Jack Whelan
617-820-5145
jack@whelanusa.com

MICHIGAN

Carl & Susan Stoel
734-254-0509
stoecarl@yahoo.com

MINNESOTA

Minneapolis/St. Paul

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

MISSISSIPPI

Bill Paul
901-767-6630
billpaultax@gmail.com

MISSOURI

Northwestern (KC Area)

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

MONTANA

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

Regional Contact:

Cindy Furst
970-227-4686
cindyfurst@gmail.com

NEVADA

Eastern

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

NEW ENGLAND

Western MA, VT & CT

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

NEW ENGLAND (cont.)

Boston and surrounding areas

Jack Whelan
617-820-5145
jack@whelanusa.com

NEW MEXICO

Albuquerque

Ginny-Kay Massara
505-256-9806
ginnykay1@juno.com

Southern New Mexico

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

NEW YORK

NE New York/

Western New England

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

New York City

Mitch Orfuss
646-352-4476
morfuss@aol.com

Syracuse/Rochester/Buffalo

and surrounding areas

Stephen E. French, Sr.
585-621-3317
sfrench@rochester.rr.com

NORTH CAROLINA

Western/Central

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

Northeastern

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

NORTH/SOUTH DAKOTA

Regional Contact:

Cindy Furst
970-227-4686
cindyfurst@gmail.com

EASTERN OHIO

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

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

WESTERN OHIO

Marion Petry
bearpaw@earthlink.net
937-438-8850

OKLAHOMA

Western

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



IWMF SUPPORT GROUP CHAPTER LISTING

OREGON/ SW WASHINGTON

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

PENNSYLVANIA

Philadelphia

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

Harrisburg, Central and Southeast PA & Northern MD

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

W. PENN, E. OH, WV

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

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

RHODE ISLAND

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

SOUTH CAROLINA

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

TENNESSEE

Central & Western

Bill Paul
901-767-6630
Billpaultax@gmail.com

Eastern

Regional Contact: Myrna Daniel
423-837-3537
mdmermer@yahoo.com

TEXAS

Dallas

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

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

Houston

Don & Kathy Knop
281-589-6621
donandkathy828@gmail.com

Western

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

UTAH

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

VIRGINIA

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

Northern

Lu Kleppinger
703-255-9878
lukleppinger@verizon.net

WASHINGTON

Northwest (Seattle Area)

Peg Horton
360-874-6906
peggyhorton@q.com

Southwest (Portland Area)

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

WASHINGTON, D.C.

Marilyn Bandel
410-489-7875
ambandel@verizon.net

WISCONSIN

Northwest WI

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

Southeast WI

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

WYOMING

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

Regional Contact:

Cindy Furst
970-227-4686
cindyfurst@gmail.com

INTERNATIONAL SUPPORT GROUPS AND CONTACTS

AUSTRALIA

Andrew Warden
andrew.warden@bigpond.com
Peter Carr
wmozzies@yahoo.com
+61 75 5529 0518

BELGIUM

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

CANADA

Alberta

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

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

Montreal

Regional Contact:

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

Nova Scotia

Ron Ternoway
1-866-768-8467
902-275-3249
rternoway@eastlink.ca

CANADA (cont.)

Ottawa

Janet Cherry
613-596-1413
janet.parcher.cherry@sympatico.ca

Toronto

Arlene Hinchcliffe
905-337-2450
ahinchcliffe@wmfc.ca
ace@nococanada.ca

Vancouver

Charlene Kornaga
250-474-7011
mykensingtonhouse@gmail.com

EUROPEAN WM NETWORK

Marlies Oom, secretary
+31 73 5217643
secretary@ewmnetwork.eu

FINLAND

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

FRANCE

Patrice Ostermann
+33 (0) 622 347 426
+33 (0) 561 712 525
pat.ostermann@orange.fr

GERMANY

Morbus Waldenstrom (MOWA)

Anita Waldmann
+49 (0)61 423 2123
a.waldmann@LHRM.de
buero@LHRM.de

GREECE

Alexia Kapralou
+30 210 6858574
kapralou_alexia@hotmail.com

INDIA

Regional Contact:

Anil and Vasundhara Somani
+91 98300 49300
anilksomani@gmail.com

Mumbai & Western India

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

IRELAND

Sheila Thomson
sheilathomsonmail@gmail.com
+35312822481

ISRAEL

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

THE NETHERLANDS

Netherlands – CMWP

www.cmwp.nl
Marlies Oom
00-31-73- 521 76 43
moom@planet.nl

NEW ZEALAND

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

UNITED KINGDOM

WMUK

Roger Brown, Patient Contact
+44 001 73735733
info@wmuk.org.uk
www.wmuk.org.uk

Birmingham & West Midlands

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



THE LIFELINE

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

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

TREATMENTS

2-CdA (CLADRIBINE) WITH RITUXAN

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

BENDAMUSTINE

Leslie Neustadt 518-374-8607
lesbn96317@aol.com

BORTEZOMIB DEXAMETHASONE & RITUXIMAB (BDR)

Joe Gallo 941-493-1809
galljocon@verizon.net
 Ron Linford 865-657-9895
rongl@aol.com

CARLFIZOMIB

Mindy Caplan 504-309-2247
mindycap@yahoo.com

CHLORAMBUCIL

Janice Stein 415-346-6620
janicemstein@aol.com
 Roy Parker 303-470-6699
roypar@gmail.com

CRYOGLOBULINEMIA

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

FLUDARABINE with cyclophosphamide (Cytosan)

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

FLUDARABINE with Rituxan

Jerry Block 301-460-9799
jblock35@comcast.net

IVIg

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

OFATUMUMAB

Rob Clark 518-298-2611

ORAL CYTOXAN

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

PERIPHERAL NEUROPATHY

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

PLASMAPHERESIS

Fred Bickle 805-492-4927
Flb134@msn.com
 John Borchert 440-449-1662
gdvibes@sbcglobal.net
 Fay Langer 904-625-3135
fhlanger@gmail.com

R-CVP

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

(revlimid) LENALIDOMIDE

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

RITUXAN

Ryan Scofield 312-576-9429
ryanscofield@gmail.com
 James Townsend 352-376-3664
 Allen Weinert 360-683-3495
anweinert@gmail.com
 Mel Horowitz 518-449-8817
wmcure@yahoo.com

SPLENECTOMY

Kathleen Ugenti 631-470-0971
Vugenti1@optonline.net
 Patricia McCue 239-348-3456 winter
 802-468-5779 summer

STEM CELL TRANSPLANTS

AUTOLOGOUS

Doug Bentley 805-937-3619
cpbentley@hotmail.com
 Howard Donley 307-587-3397
donleyh@tctwest.net
 Scott Blazek 651-730-0061
mandsblazek@aol.com

ALLOGENEIC

Eileen Sullivan 617-625-6957
Ebsullivan27@gmail.com
 Melissa Sawyer 303-979-1765
sawyerirish@aol.com

THALIDOMIDE

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

SUBCUTANEOUS VELCADE

Tom Zolezzi 518-475-1514
tkzolezzi@yahoo.com

SPECIALTY TOPICS

AFFORDABLE CARE ACT

Leukemia and Lymphoma Society "Need to Know", FAQ's and Glossary: <http://www.lls.org/#/diseaseinformation/getinformationsupport/aca/> Live Chat: 800-955-4572

CAREGIVING

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

CLINICAL TRIALS

Tom Hoffmann 501-868-8305
Thh97@msn.com
 Guy Sherwood 765-282-4377
guysherwood@comcast.net

HEARING IMPAIRED TTY FACILITY

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

IBRUTINIB

Mitch Orfuss 646-352-4476
morfuss@aol.com
 Hank Stupi 804-758-4096
hstupi@hotmail.com

MILITARY VETERANS

Daniel Costigan 952-841-0174
dancostigan@hotmail.com
 Glenn Ross 305-808-4170
Glenn.Ross@vitas.com
 GSR060647@aol.com 214-317-9494

MGUS

Mary Beth Nevins 203-375-7748
mbnev@sbcglobal.net

NEWLY DIAGNOSED

Guy Sherwood 765-282-4377
guysherwood@comcast.net
 Sallie Moore 516-795-3746
Smoore6042@aol.com

SOCIAL SECURITY DISABILITY

Howard Prestwich 815-233-0915
prestwic@mwci.net
 National Organization of Social Security Claimants (NOSSCR) www.nosscr.org

WATCH AND WAIT

Mel Horowitz 518-449-8817
wmcure@yahoo.com
 Guy Lithwin 843-234-3310
glithwin@sccost.net
 Renee Paley-Bain 203-744-7851
paleybain@aol.com



THE LIFELINE

WATCH AND WAIT (cont.)

Joel Rosenblit 503-365-7074
rosenblitj@msn.com

YOUNG WM

Ryan Scofield 312-576-9429
ryanscofield@gmail.com
 Bob Bailey Cell 770-633-3536
Bbailey@rune2e.com Wife's Cell 770-361-4859
Laurabailey64@gmail.com
 John Borchert 440-449-1662
gdvibes@sbcglobal.net

INTERNATIONAL

ARABIC SPEAKER

Sherine Elsawa, Ph.D. 815-753-7839
selsawa@niu.edu

AUSTRALIA

Colin Perrott
Wmozzies-owner@yahoo.com
colin@wmozzies.com

BELGIUM

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

EUROPEAN WM NETWORK

Marlies Oom, secretary +31 73 5217643
secretary@ewmnetwork.eu

FINNISH SPEAKER

Veikko Hoikkala +3585500484864
veikko.hoikkala@dnainternet.net

FRENCH SPEAKER

Guy Sherwood 765-282-4377
guysherwood@comcast.net
 Patrice Ostermann +33 (0) 622 347 426
pat.ostermann@orange.fr +33 (0) 561 712 525

WALDENSTRÖM FRANCE

<http://portail.waldenstromfrance.org/>
contact@waldenstromfrance.org

FRENCH LANGUAGE TALK LIST

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

GERMAN SPEAKER

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

GERMAN LANGUAGE TALK LIST

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

JAPANESE SPEAKER

Tony Undo Otani
adyna@msn.com

SPANISH SPEAKER

Peter Mitro Ohio 216-591-1004
stonehill@earthlink.net Florida 561-495-4299
 Betsy Beazley 510-527-5827
betsybeazley@gmail.com
 Gladys Mendieta 215-860-9216
Gladysmendieta@aol.com
 Leon Maya 865-694-9581
leonmaya55@gmail.com
 Brad Smith (Hawaii) 808-594-8917
becandbrad@gmail.com

SPANISH LANGUAGE TALK LIST

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

SWEDEN/NORWAY

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

NORDIC COUNTRIES TALK LIST

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

UNITED KINGDOM LIFELINE

2CdA (CLADRIBINE)

Roger Brown +44 0117 3735733
info@wmuk.org.uk

FLUDARABINE

Ken Ridout +44 1278 782108
ken.4rosetree@talktalk.net

OPHTHALMOLOGY

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

PLASMAPHERESIS

Roger Brown +44 0117 3735733
info@wmuk.org.uk

RITUXAN

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

STEM CELL TRANSPLANT - AUTOLOGOUS

Roger Brown +44 0117 3735733
info@wmuk.org.uk

WALDENSTROM'S MACROGLOBULINEMIA

UK CANCER SUPPORT

Roger Brown +44 0117 3735733
info@wmuk.org.uk
www.wmuk.org.uk

WMUK ONLINE FORUM

Roger Brown
info@wmuk.org
 Phil Manning
phil.manning55@btinternet.com

CANADA LIFELINE

CLINICAL TRIALS

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

TTY- HEARING IMPAIRED

Betty McPhee (Toronto, ON)
bjmcphee@hotmail.com
 Fluent in American Sign Language

NEWLY DIAGNOSED

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

CVP/RITUXAN

Betty McPhee (Toronto, ON) 647-348-7440
bjmcphee@hotmail.com
 Ritwik Ray (Toronto, ON) 416-693-0910
ritwik@rogers.com
 Rod Anderson (Cobourg, ON) 905-372-2410
rod@rodmer.com

FLUDARABINE

Gary Dvorkin (Mississauga, ON)
fgdvorkin@gmail.com

RITUXAN

Rod Anderson (Cobourg, ON) 905-372-2410
rod@rodmer.com
 Gary Dvorkin (Mississauga, ON)
fgdvorkin@gmail.com
 Susan Gagnon (Halifax, NS)
suemarg3x3@hotmail.com

VELCADE

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



**SINCE MARCH 2014, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

Harry Abramoff
Kimiko Ise Abramoff

Marvin Arenson
Arlene Arenson

Shelly Arkin
Fred Abrahams

Jeff Atlin
Carl Harrington & Eleanor Levie
Sue Herms
Michael & Gerri McDonald

Sai Baba
Geetha Gangadharan

Paul Balfe
Earl Nolting

Freddy Bastin
Nicole Bastin

Roland Beck
Dorothy Beck

Robert Bent
Mary Bent

Irene Bilsbrough
Terry Bilsbrough

Patricia Boudreau
John & Betty Barclay
Duff & Maryanne Linsell
Margaret Nelson
Alex & June Salehi
Robert & Norma Smith

Richard Cannone
Barbara Cannone

Felix Cohen, M.D.
Stephen & Frieda Cohen

Wilbur V. Cole, D.O.
Harold & Dorothy Schultz

Arthur Connolly Jr.
Ramon & Karla Tobar

Robert Coulbourn III
Bennett Wethered

Bill Cunningham
Don Bain & Renee Paley-Bain

Kay Decker
Elizabeth Howanski

Ron Draftz
Jean Arndt
Neal & Judith Makens

John Dziedzic
Carolyn Olson

Hardy Edward
Dottie Hardy

Carl Ekroth
DEP Friends
The Employees at VHG Labs

George Farrier
Margaret Farrier

Laurie Faulkner
Neal & Judith Makens
Cynthia Masters

John Flanzer
Harold & Gloria Flanzer

Jerry Fleming
Phillip Cacioppo

Jack Gelber
Don Bain & Renee Paley-Bain

Anne Greene
Jerry & Kristine DeWitt
Jenny Laster Genser
Michael Greene
Sue Herms
David & Helen Herron
Hiroyuki & Atsuko Ikeda
Elaine Katz
Glenn & Marcia Klepac
Judy Mutt
Catherine Naylor
John & Penelope Paasch
C. William & Meredith Savery
Gustavo & Laura Verdun
Horacio Verdun

John Griffin
Alden & Doris Halloran

Gene Hammel
Bernard & Carolann Cohen

Richard Haney
Dawn Haney

Paul Hendricks Jr.
Tom & Eloise Cathcart

Lydia Housner
Jimmie Darnell

Louis J. Huskins
Jeff Prupis & Wanda Huskins

Mary Jacquelin Junk
Donald & Monica Gliem

George Katz
Francine Varady

Cheryl Kuhn
John Kuhn

Bill Leiva
Costco Wholesale Texas
Region Non-Foods Dept.

George Linsley
Laurence & Ellen Barnes
Thomas & Donna Baum
Katherine Blackwell
Mary Blanchard & Diane Sautter
Capital District Library Council
Robert Curto & Lois Maruska
William Foley Sr. & Maryann Foley
Carol Gerard
Kenneth & Daria Henry
Theodore & Elizabeth Jean
James & Grace Jukes
Ronald & Barbara Kurdyla
Mark & Mary Lyon
Charles & Shirley Maguire
William & Pamela Phelps
Ken & Michelle Relation
Edward Sindoni Jr. & Lynn Sindoni

George Linsley (cont.)
Terry & Alisa Stickle
Patricia Vartigian
John & Fran Williams

Anne Mann
Don Bain & Renee Paley-Bain

Maxine Masek
John & Genevieve Lucas

Jeanne Milton
Richard Lilley

Sallie Moore
Academy for Global Citizenship Staff
Don Bain & Renee Paley-Bain
Theresa Bendel
Bonnie Bonnaviat
Raul Cuza
Vivian Ellner
Melissa Fulgieri
Elaine Kelly
Bernard & Karin Miller
Jennifer Moore
Leon & Margaret Moore
Virginia Rubin
Steve & Peggy Shapiro
UN International School Library
UNIS Parents Association
UNIS Staff Association
Michal Urieli
Linda Willner
Virginia Zimmerman

Carolyn K. Morris
Maynard Morris

Ardis Murkerson
Will & Jean Edgar
Sam & Doris Mathis

Karen Parker
George & Lisa Teal

Sharon Potesman
Stevenson Band Parents

Ben Pumilia
Gail Pumilia

Elsie Ann Rashford
Cinda Spavins

Robert Reed
Connie Reed

Neil Rehrer
Susan Rehrer

Hank Rimmer
Chris Rimmer

Barbara Roberts
Alden & Doris Halloran

R. Waldo Roberts
Alden & Doris Halloran

Susan Rubenstein
Ruth Brady

George Saretsky
Ann Saretsky



SINCE MARCH 2014, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

Brian Schaefer
Cheryl Buttino

Ian Singe
Raymond Valadez & Rose Crownover

Estella Singer-Abrams
Raymond Valadez & Rose Crownover

Bill Toflinski
Paula Austin

Charles Vassallo
Lucrezia Vassallo

SINCE MARCH 2014, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

Dr. Rafat Abonour
Angelique Draftz

All those responsible for putting on the Ed Forum
David & Penny Kirby

All Waldenstrom's Patients
Ronald & Martha Kowalski

Joan Berglund
Joel Rosenblit

Michelle Blazek
Nick & Germaine Blazek

Roseanne Brandon
Paul Hayslett

Donna Burgei
Ronald & Donna Burgei

Daniella Crownover
Raymond Valadez & Rose Crownover

Zachary Crownover
Raymond Valadez & Rose Crownover

Mark Davey
Jim & Pat Davey

Peter DeNardis
Edward Goldberg & Linda Trytek
Andrew Warden

Jane Dobies
Karen Dobies

Marty Edelman
Jerry Abrams
Jim Bakle
John Bartlett
Wayne Bigelow
Bernie Ditchik
Klaus Eberius
Rich Epstein
Fred Erman
Marty Hauselman
Lennie Lawrence
Al Lowe
Jack Marck
Aldo Massara
Kent McCreight
John Myles
Jack Paterson
Dave Poelke
Mike Tighe
Manfred Welfonder

Maureen Foley-Marenco
Brett Marenco

John Ganser
Jennifer Ganser

Ali Handal
The Handal Foundation, Inc.

Carl Harrington
Maurice & Ruth Levie

Nancy Hess
Joe Brohas

Jack Honaker
Sarah Fitori
Drew Honaker

Edward Isaac
Camille Coiro
Carolyn Goldstein
Ross Miller

IWMF Volunteers
John & Penelope Paasch

K. Edward Jacobi
Ellen Peifer

Robert Kelson
Ann Marie Kelson

Ellis Kennedy
Lewis University College of Education

Jaya Mani
Ajoy Mani

Neil Massoth
Bruce & Ruth Bier
Pauline Bier
Ken & June Cohen

Christopher Moakley
Julie Moakley

Rachel Ortiz
Raymond Valadez & Rose Crownover

Nancy O'Soro
John & Lynn Lopes

Annika Pedersen
Lloyd & Sheila Hoffman

Mike Pennington
Karen Blocksom

Anna Mae Quitter
Janine Quitter

Alice Riginos
Cynthia Riginos

Gerri Roberts
Sam & Doris Mathis

Ryan Scofield
Richard & Karen Scofield

Scramble for WM Golf Outing
Cliff & Gail Baker
Paul Blucher

Scramble for WM Golf Outing (cont.)

Charlie Cahill
Valerie Cloud
Larry & Carolyn Hand
Deborah Haufler
Jackson Jones
David & Penny Kirby
Lynn Kokott
Terry & Patty Labarge
Sara McKinnie
Bobby Ollerhead
Mark Pena
Stephen & April Warenchak

Michael Sesnowitz
Douglas Sesnowitz

Marion Shore
Raymond Valadez & Rose Crownover

Robert Shustak
Donald & Rose Shustak

Judge Scott Silverman
Reeva Sterling

Bradstreet Smith
Matthew Smith

James Spivey
Carole Spivey
Anne Staples

Dr. Scott Stone
David & Mary Rist

Dr. Steven Treon
Arlene Arenson
Hans Forster

Ray Valadez
Rose Crownover

Ubaldo Vitali
Bruce & Judy Bernbaum
Anita Vitali

Daryll Wartluft
Lisa Anderson

Lisa Weldy
Mort & Judy Weldy

Andy Westrich
The Woman's Club
of Williamsburg-GFWC

Marcia Wierda
William & Joyce Buis
Mary Olsen
James & Diane Stuck
Richard & Debbie Stuck
Betty Lou Ter Haar
Andy & Tracie Wierda



chemotherapy. In many instances plasmapheresis (using a machine similar to dialysis to temporarily remove IgM from the blood) done in the days preceding infusion of rituximab is recommended to prevent symptoms of the so-called rituximab IgM flare.

Summary

There is no substitute for becoming as well informed as you can be regarding your disease and the specific treatment

proposed for you. Avail yourself of the great resources of the IWMF and especially of the professionals taking care of you – your doctor and nurses.

I wish to thank Megan Andersen, NP, who has been such a valuable resource to our WM patients in the Rocky Mountain region and who contributed to this review. Thanks are due as well to the IWMF, to WM researchers worldwide, and, most of all, to the great WM patients.

Diagnosis and Management of Anemia, cont. from page 11

macroglobulinemia, with regimens that include rituximab and/or fludarabine. For anemic patients who do not have significant Waldenström involvement in the bone marrow, screening should be done for cold agglutinin disease. Screening is extremely simple and requires only two tests: 1) a reticulocyte count and 2) a Coombs test, which is commercially available in every laboratory in the United States.

Screening for B12 deficiency may be appropriate for selected patients.

A very rare cause of anemia is dilutional anemia where high levels of IgM cause movement of fluid into the circulation, diluting the number of red blood cells and causing a decline in the hemoglobin level that does not actually reflect a reduction in oxygen-carrying capacity. This is an extremely rare cause of anemia and is limited to those patients with very high levels of IgM.

It is important to distinguish anemia due to Waldenström from anemia due to the treatment of the Waldenström. Many of the agents that are used in the treatment of Waldenström macroglobulinemia have an effect on normal cellular production in the bone marrow and can actually aggravate anemia. This is simply another way of saying that chemotherapy can damage the good cells as well as the bad (Waldenström) cells. Therefore, in the case of patients under treatment for Waldenström, caution must be exercised to distinguish anemia that is due to progressive Waldenström from anemia due to the treatment of Waldenström. In the latter case, anemia will likely improve after treatment has been completed. Patients who develop progressive anemia while their IgM level declines should be suspected of having therapy-related anemia. Particular attention should be paid when treatment includes lenalidomide because two separate groups have reported that it aggravates the anemia of Waldenström.

Therapy

The best therapy for most patients who have anemia is treatment of the underlying Waldenström. Making the bone marrow healthier will result in better red cell production. As noted above, if iron deficiency is a problem, replacement of iron can improve the hemoglobin.

Finally, there are chemical agents that stimulate the bone marrow to increase red blood cell production and that are particularly useful if patients have impaired kidney function with their Waldenström. These agents, known as erythropoietin and darbepoetin alfa, are no longer used frequently because the FDA has identified these agents as potentially increasing the risk for death, heart attack, and stroke. Therefore, the lowest possible dose is recommended if these drugs are required. Moreover, in certain cancer types (including breast, lung, head and neck, lymphoma, and cervical cancer), these agents have shortened overall survival. So again, if required, the lowest dose of either erythropoietin or darbepoetin alfa needed to avoid transfusions is recommended.

Conclusion

In summary, for the majority of Waldenström patients, anemia is directly due to the disease, and effective treatment of Waldenström is the best intervention for anemia. If the level of hemoglobin declines following completion of treatment, it is possible that this anemia results from the treatment. Mild anemia need not be treated. Patients who are anemic but have a low percentage of Waldenström cells in the bone marrow should be screened for blood loss in the colon or stomach, as well as for cold agglutinin disease, iron deficiency, and, rarely, B-12 deficiency.

Dr. Morie A. Gertz is Chair, Internal Medicine, at Mayo Clinic. In his clinical practice he has evaluated and treated patients with Waldenström's macroglobulinemia for more than thirty years. Dr. Gertz's talk, "Burning Questions About WM," which was delivered at the Tampa Ed Forum, is available in video at the IWMF website. This is a presentation that should not be missed!





Non Profit Org
US Postage
PAID
Manasota, FL
Permit No. 133

International Waldenström's
Macroglobulinemia Foundation
6144 Clark Center Avenue
Sarasota, FL 34238

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

E-mail: info@iwmf.com • www.iwmf.com

IWMF is a 501(c)(3) tax exempt non-profit organization

Fed ID #54-1784426

International Scene, cont. from page 16

CART-WHEEL generates non-identifiable data for research analysis on disease progression and treatment effectiveness. CART-WHEEL database contains personal details, family history, doctors, hospitals, cancer type, treatment, blood test results (IgM), side effects and adverse events. The database content is based on recommendations of A/Professor Judith Trotman, Sydney University and Senior Staff Specialist and Director, Clinical Research Unit in the Haematology Department, Concord Hospital. It is intended to widen usage of CART-WHEEL from just WM to include all blood types to increase greatly the project's research value. The Leukaemia Foundation has agreed to use their contact database to invite over 230 Australian WMers to participate in CART-WHEEL. Visit www.cart-wheel.org/ for more information.

WMozzies is exploring ways to advocate for an update to the **clinical practice guidelines** for the diagnosis and management of WM. Our goal is to ensure that Australians can access the best WM treatment options available and to identify and address any shortfalls from WM world-best practice.

A **web-based donations facility** is being developed. Prospective research projects to be funded include updating of WM treatment guidelines and funding for "Young WM Investigators" to attend WM specialist conferences such as IWWM-8 in London.

The **IWMF Educational Forum** and the Support Group Leaders Workshop in Tampa, Florida, was attended in May by Peter Carr on behalf of WMozzies. He met with several of the IWMF Trustees, including Dr. Kyle, to discuss WMozzies

issues including the List of Australian WM Doctors. Peter was very grateful for the wonderful welcome and assistance given to him by the IWMF Trustees. Having attended the Las Vegas conference five years ago, Peter came away from the 2014 Forum very excited about the progress made in research and treatment options.

The directory of Australian WM doctors has received further deliberation with the Australian hematologists following the discussion at the IWMF Ed Forum. An alternative is now favoured. It is considered better for the local consulting hematologist practice to be contacted to identify a hematologist willing and able to provide a consultation for a patient with WM. In NSW and ACT, lists of doctors by cancer type and location are readily available on the *Canrefer* web directory, see www.canrefer.org.au/ Other reference links will be included on the WMozzies web site when identified.

Ways for **bone marrow samples** from WM Ozzies to be included in a major IWMF research project are being explored. The research by Dana-Farber Cancer Institute at Harvard University, Boston, US, with IWMF funding has helped establish a tissue bank along with an epidemiology study of patients with Waldenström's. Until now there have been logistical constraints to sending tissue samples from Australia. Dialogue is advancing to allow WM Ozzies to join more than 1,000 WM patients already part of the research to examine further the genomic and epigenetic regulators of tumor progression in Waldenström's.

Peter Carr and Andrew Warden reporting.

This issue of the Torch newsletter is sponsored by:

 **NOVARTIS**
ONCOLOGY