

INSIDE THIS ISSUE

Doctor on Call:
Morie A. Gertz..... 1

President's Corner 4

Treasurer's Report 5

Make Your Plans
Now for the
2014 Ed Forum! 6

A Taste of Tampa 7

Imbruvica Wins FDA
Approval for
Lymphoma 7

Medical News
Roundup 8

What's in
Our Name? 10

From IWMF-Talk..... 10

To Screen or Not to
Screen? That is the
Question..... 12

Cooks' Happy Hour ... 14

Caregivers are
also Survivors 15

Creative Giving –
What's Your Idea? 18

Support for the Dads... 21

Fifth International
IWMF Doctor-Patient
Forum in London 22

International Scene.... 22

Support Group
News 26

DOCTOR ON CALL: MORIE A. GERTZ, M.D.

LATE (AND RARE!) COMPLICATIONS OF WALDENSTRÖM MACROGLOBULINEMIA



Dr. Morie A. Gertz

Classification of Waldenström Macroglobulinemia

Waldenström macroglobulinemia is a form of malignant lymphoma. The technical terminology is lymphoplasmacytic lymphoma. Physicians who specialize in the field classify lymphoma into three types: low-grade, intermediate-grade, and high-grade. The grading assigned to a specific lymphoma reflects how biologically aggressive it is. Waldenström macroglobulinemia is referred to as a low-grade lymphoma. Low-grade means that the tumor tends to grow slowly, that very few of the cells are actually dividing at any one time, and that the genetics of the lymphoma are favorable.

With current technology, it is possible to analyze the genes and chromosomes of patients with Waldenström macroglobulinemia and other types of lymphoma. In many lymphomas, it is possible to find genes that predict for resistance to chemotherapy, poor response to rituximab, or rapid regrowth of the lymphoma after chemotherapy is administered. The gene abnormalities that predict this type of poor outcome following chemotherapy are only rarely seen in Waldenström macroglobulinemia. As a result, patients with Waldenström tend to have high response rates and a long duration of response; and in this regard, the genetics are “favorable.”

In fact, if one took a single Waldenström cell and placed it under the microscope for inspection, it would be difficult to identify that single cell as cancerous. A diagnosis of Waldenström can be established because there is a high percentage of these cells in the bone marrow. A biopsy is always required to establish a diagnosis of Waldenström. This most commonly occurs through the bone marrow, but occasionally a diagnosis can be made by biopsy of a lymph node. Virtually all patients with Waldenström require a bone marrow examination. Waldenström cells may be diffuse throughout the marrow or they may be grouped in clusters.

The low-grade designation is very good news for Waldenström patients, and this favorable biology is a major reason why the outcomes with treatment are so favorable. Typically, effective therapy shrinks the Waldenström population and can allow for years of durable response because the tumor regrows very slowly after a treatment is halted.

Large Cell Transformation (Richter's Syndrome)

Another reason why Waldenström macroglobulinemia is classified as low-grade is that as the cell evolves from its parentage it becomes progressively more mature. Waldenström cells develop in one of two ways. In the first, a Waldenström cell divides and forms two Waldenström cells. This is not the only possible way in which Waldenström cells develop. In fact, most Waldenström cells are incapable of dividing or divide very infrequently, perhaps not even annually.

The other way a Waldenström cell can develop is from a more primitive lymphoma cell that “grows up.” This really means that the cell matures from a more primitive “parent.” Waldenström cells

Late (and Rare!) Complications, cont. on page 2

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

Marlyn Friedlander

Peter DeNardis

Marty Glassman

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.

Late (and Rare!) Complications, cont. from page 1

can be found in the bone marrow, liver, spleen, and lymph nodes. The cells, actually as they grow, will exit the bone marrow, undergo processing in lymph nodes, and then return to the bone marrow. The standard for the Waldenström cell is to start as a less mature cell and become progressively more mature with time. This maturation is an inherent property of all cells of the body. Unfortunately, in a small proportion of patients with Waldenström who have typically lived with the disease for many years, the Waldenström cell may lose its ability to mature from an immature parent B-cell into the more mature Waldenström cell. In general, as a cell matures, it shrinks in size from a larger cell to a smaller, more compact cell. In instances where genetic changes occur that prevent the maturation of the Waldenström cell, development will sometimes stop at an intermediate stage where the cell is referred to as a "large cell."

Dr. Richter of the University of Minnesota first recognized this blockage in maturity of the lymphoma cell at a point when it does not mature beyond the large cell stage. Initially this block in maturity was erroneously supposed to represent a transformation of the lymphoma to a new type. But what actually occurs is a block in the ability of the lymphoma cell to mature. This block, which is referred to as large cell transformation, now bears the name of the doctor who recognized it and is referred to as Richter's transformation or Richter's syndrome. The most common type of lymphoma associated with intermediate maturity is diffuse large-cell B-cell lymphoma (DLBCL). All types of lymphoma, not only Waldenström, can undergo Richter's transformation to DLBCL.

Large cell transformation (Richter's syndrome) represents a change in the biologic behavior of Waldenström lymphoma. The resulting large cells tend to have more genetic abnormalities, and they tend to have a faster growth rate. As a consequence, when large cells develop, they require a more aggressive form of treatment. Treatment of patients with Richter's syndrome usually requires some chemotherapy medications that are not often used in the treatment of Waldenström macroglobulinemia. Since all the Waldenström's cells do not transform, patients have coexistent Waldenström and DLBCL.

Moreover, one possible complication arises because many patients have been exposed to various treatments over the years for their Waldenström. For such patients there is the potential for inherent chemotherapy resistance.

Purine nucleoside analogs such as fludarabine and cladribine have been implicated as a potential risk factor for the development of Richter's transformation. Fortunately, the risk is low and it often occurs late. Patients and their physicians should discuss this risk before reaching a decision to proceed with fludarabine or cladribine therapy. The treatment is highly effective in the management of Waldenström, and all treatments carry side effects and toxicities, so that a risk-versus-benefit assessment is warranted.

Late (and Rare!) Complications, 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

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.

Caution should be exercised when considering purine nucleoside analogs as a treatment option.

Large cell transformation can also occur in Waldenström patients who have never been treated. Fortunately, this is such a rare occurrence that it usually is not a critical factor when decisions are made concerning treatment selection for patients. Cancer cells are genetically unstable and, thus, can change over time. Therefore, it is possible for lymphomas to change from low-grade (Waldenström) to intermediate-grade (DLBCL) even in the absence of therapy. However, this risk is only for a very small percentage of patients.

Signs of large-cell transformation may include a sudden enlargement of a single lymph node or the development of nighttime fevers or drenching sweats. The blood test for lactate dehydrogenase (LDH: part of routine blood chemistry) can rapidly rise. In all instances, a biopsy is required to establish the presence of large-cell transformation. Oftentimes, a PET (positron emission tomography) scan will show enhanced uptake in a transformed lymph node. Fortunately, diffuse large-cell B-cell lymphoma is a highly treatable form of lymphoma and can be controlled.

Central Nervous System Lymphoma (Bing-Neel Syndrome)

When Waldenström cells move out of the bone marrow they tend to collect in certain organs, usually limited to the bone marrow, liver, spleen, and lymph nodes throughout the course of the disease. The presence of Waldenström is generally restricted to these organs because the cells have a peculiar “stickiness” that keeps them within those specific sites. In rare instances late in the disease, the Waldenström cells can lose their sticky quality and begin to involve other organ systems. When this occurs the disease is referred to as ‘extramedullary disease.’ Occasionally, Waldenström cells can invade the central nervous system (CNS), which describes the brain, spinal cord, and meninges (the membranes that cover the brain and spinal cord). The development of Waldenström macroglobulinemia cells in the central nervous system was first described by Drs. Bing and Neel and carries their names as the Bing-Neel syndrome. A more accurate description would be CNS involvement with Waldenström macroglobulinemia.

Central nervous system involvement with Waldenström macroglobulinemia comes in two forms. The first is in the form of actual tumors that develop within the brain substance and cause problems such as seizures or paralysis. These tumors are typically treated with radiation therapy directly to the tumors combined with chemotherapy designed to cross into the central nervous system.

The second form of central nervous system involvement is in the form of meningitis, in which case individual cells involve

the central nervous system without causing tumors. This spinal inflammation, due to the Waldenström cell accessing the central nervous system, can cause damage to the cranial nerves in the form of headaches, confusion, neck stiffness, and sporadic loss of motor function. Other symptoms can include facial paralysis, drooping eyelid, double vision, or swallowing with difficulty. These are changes associated with damage to the cranial nerves in the brainstem of the central nervous system. Rarely, the cranial nerves that control vision (cranial nerve II) and hearing (cranial nerve VIII) can be involved leading to visual or hearing loss.

This “lymphomatous meningitis” is a very dangerous complication of Waldenström and requires aggressive therapy to eradicate it. The treatments for Bing-Neel syndrome include radiation to the central nervous system and chemotherapy directly administered into the spinal fluid space. Oftentimes, intravenous chemotherapy in high doses that can cross into the spinal fluid will be concomitantly administered to help promote control of the disease. The usual chemotherapy agents are generally not usable because the central nervous system is a “protected site” where chemotherapy will not cross over. Physicians refer to a “blood-brain barrier” to indicate that medications administered through the bloodstream generally cannot access the central nervous system because of this protective barrier. For this reason, the chemotherapy may have to be administered directly into the spinal canal. Bing-Neel is rare and, as a consequence, for the management of Bing-Neel it is wise to turn to a team with experience in this syndrome. Such a team generally will include both a neurologist specializing in malignancy as well as a Waldenström expert.

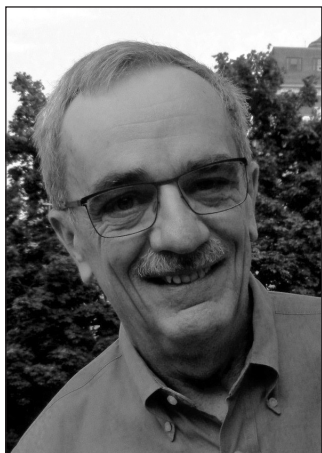
Conclusion

Although both Richter’s syndrome and central nervous system lymphoma are serious complications of Waldenström macroglobulinemia occurring late in the course of the disease, both complications are treatable. And, fortunately, both are so rare that most oncologists, even those whose practices include a number of Waldenström patients, never see these complications during their entire career. The complications of Waldenström, both Richter’s transformation and Bing-Neel, are generally not seen early in the course of Waldenström and almost never when patients have it for a short period of time. Typically these developments occur when one has had the disease for many years, usually but not exclusively, after extensive therapy.

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 serves on the Scientific Advisory Committee of the IWMF.



PRESIDENT'S CORNER



Marvin Gaye (1968). In homage to those times and to “best of” lists in general, here are my personal top IWMF/WM “hits” of 2013:

Breakthrough Therapy Designation of ibrutinib by the U.S. Food and Drug Administration for WM and mantle cell lymphoma. This was the first designation of Breakthrough Therapy for *any* cancer drug, and it means this drug is on a fast track for approval.

Major new IWMF research grants funding Dr. Steven Treon at Dana-Farber Cancer Institute (DFCI), Dr. Sherine Elsawa at Northern Illinois University, and Dr. Ruben Carrasco, also at DFCI. Dr. Carrasco's project is jointly funded by the Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) and by the Leukemia & Lymphoma Society (LLS).

The spectacular, full-color fifteenth anniversary Torch issue.

LLS collaboration: I visited the LLS in May to review the success of our joint WM cell line project. In December I met Dr. Lee Greenberger, the new Chief Science Officer of LLS, at the annual meeting of the American Society of Hematology in New Orleans, together with Dr. Robert Kyle and Dr. Steven Treon, to discuss new collaborations. Stay tuned to hear more about future joint efforts.

IWMF Member Services improvements, including downloadable booklets and the newly updated *Treatment Options*.

LRF collaboration: I visited the LRF (Leukemia Research Foundation) in May and attended the LRF Ed Forum in Brooklyn in September. I also had the opportunity to meet the new LRF President, Liz Thompson. Quite coincidentally, her brother was recently diagnosed with WM.

Our very successful Ed Forum in San Diego.

A new year is the perfect time not only for making resolutions but also for reflecting on the best of the year just passed. I can clearly remember my teenage years, listening intently as the radio DJs counted down the year's biggest hits. Back then, popular favorites included hits such as *Help!* by the Beatles (1965), *I'm a Believer* by the Monkees (1968-69), and *I Heard It Through the Grapevine* by

International progress: I met Roger Brown, the head of WMUK, in Washington, DC, while attending the meeting of the Oncology Nurses Society in May. In May I also attended the Canadian Ed Forum organized by Arlene Hinchcliffe, and recently I've been working with Roger Brown and Chris Patterson of DFCI on plans for the Fifth International IWMF Doctor Patient Forum.

The more than thirty of my friends and family who responded to my wife's request for support for the IWMF. We raised over \$10,000!

Surviving yet another year with WM and managing to stay on watch and wait with only minor issues.

What would be on your list of hits?

What to expect in 2014

What are the early picks for breakout hits in 2014? Here are four that I'm “hearing through the grapevine” and “believe” we'll be singing praises to at the end of 2014.

Ibrutinib approval. Ibrutinib was just approved by the FDA (Federal Drug Administration) for mantle cell lymphoma (see also page 7), and we hope that approval will be granted for WM in 2014. When this happens, ibrutinib will be the first drug ever approved specifically for WM.

The nineteenth IWMF Educational Forum in Tampa, Florida, at the Marriott Renaissance Hotel from May 16-18, 2014. We have an outstanding list of presenters and an intriguing theme: *Imagine a Cure: Seeds of Hope*. (See pages 6-7 for more information.)

The Fifth International IWMF Doctor-Patient Forum in London on Sunday, August 17, 2014, (see page 22 for more information) which follows the Eighth International Workshop on Waldenstrom's Macroglobulinemia. Come and learn the latest news from the best minds in WM.

Accelerating research progress. The recent progress in research is paying off. More researchers are sending us promising proposals. In fact, we have more proposals than we can support right now. If you can, now is the time to dig a little deeper and commit as much as you can. And ask your friends and family if they can support you and the dedicated researchers who are making such great progress. Without our funding, the scientists can't do their work. Without their work, we won't have better treatments or a cure. And without your asking, your friends and family may not offer support. It's up to us to rev up the music.

President's Corner, cont. on page 5



Recent News

Here's the latest news from the November meeting of the IWMF Board of Trustees. Maybe some of these items will make it onto the 2014 hit list.

For our international members, we've added *Google Translate* to our website. Now WMers everywhere can get the website translated into one of 55 languages. We're also translating all of our major booklets into Spanish, the second largest language in the world in terms of native speakers.

We are restoring the *Torch* to 4 issues a year to help you stay current with the fast changing progress in the world of WM.

We initiated a *new Advocacy Program* where we'll work side-by-side with the LLS, LRF, IMF (International Myeloma Foundation), and NORD (National Organization for Rare Diseases) to advocate for issues that affect us all. Judith May and Jack Whelan will lead our efforts.

The November meeting of the Board of Trustees marked the end of their IWMF Board terms for Tom Myers and Don Brown. Tom was part of the early backbone of the IWMF. He joined the Board in 2001 and served over a dozen years, largely as the Vice President of Research. Don joined the Board in

2008 and served six years on the Fundraising Committee. We are grateful to both of them for their exemplary service. And, personally, I'm thankful for their friendship and their unstinting loyalty to the IWMF. We'll miss them both very much on the Board of Trustees!

But, fortunately, Tom will remain on the IWMF Research Committee and Don will remain on the IWMF Fundraising Committee, so we'll retain their wisdom and keep in touch.

Further changes among the officers and members of the Board were made at the November meeting:

Our new Vice President for Research is Dr. Guy Sherwood, whom many of you know from past Ed Forum presentations, IWMF-Talk comments, and the many *Torch* articles and booklets he's authored.

Marlyn Friedlander is our newest Board member. Marlyn will serve on the Fundraising Committee. Look for an article introducing her in the April *Torch*.

Back on a musical note, "I'm a Believer" in the IWMF. I hope you are, too. In any case, if you need "Help!" in any way, turn to your IWMF family.

Together, we'll create the record hits of 2014.

Good health in 2014,
Carl

TREASURER'S REPORT AS OF NOVEMBER 30, 2013

BY CYNTHIA RUHL, IWMF TREASURER

The finances of the IWMF are accounted for through two separate funds. The Research Fund is used solely to fund research grants that the Research Committee has reviewed and recommended. The Member Services Fund provides for all of our membership services, including the Educational Forum, the website, and the *Torch*. Both funds are critically important to the work of the IWMF.

The following is a summary of the financial results for the first eleven months of 2013. The amounts are rounded to the nearest thousand and have not yet been audited. However, I wanted to share with you where the IWMF stands financially for 2013 through November.

	Research	Member Services	Total
Revenue	\$ 376,000	\$ 595,000	\$ 971,000
Expenditures	\$ 473,000	\$ 566,000	\$ 1,039,000
Net Revenue	\$ -97,000	\$ 29,000	\$ -68,000

We hope you will continue to support the IWMF throughout the rest of the year. The Research Committee has received applications for research projects worthy of funding which we cannot afford to support at present. At the recent meeting of the Board of Trustees in November, enthusiastic proposals were also made for enhancing Member Services.

The cash reserves at the end of November 2013 for the Research Fund are \$588,213 and for the Member Services Fund, \$248,900.

The financial audit for 2012 has been completed and posted to our website. As a Board Member, I can assure you that the Board of Trustees does its very best to make sure that every dollar is wisely spent on serving you, our members, and keeping important research moving forward. Thank you for your continued support.

If you have any questions, please feel free to contact me: csruhl@hrmcipas.com



MAKE YOUR PLANS NOW FOR THE 2014 ED FORUM!

The tropical Gulf Coast of Florida is the destination for the 2014 IWMF Educational Forum to be held May 16-18 in Tampa. In addition to the educational and social activities offered at the Forum, we hope that you will want to take advantage of all there is to see and do in the Tampa area. See “A Taste of Tampa” below to help you get started on your plans!

We have negotiated a special room rate of \$129 per night at the Renaissance Tampa International Plaza Hotel. This Mediterranean-themed hotel is part of the upscale International Plaza shopping and dining mall and offers airport shuttle service, as well as complimentary self-parking and valet parking. It is convenient to the Tampa International Airport, downtown Tampa, and the beaches. To make your reservations, call 813-877-9200 or Toll-Free 800-468-3571 and be sure to mention “iwmiwma” to receive the special rate. For general information on the hotel, go to <http://www.marriott.com/hotels/travel/tpaim-renaissance-tampa-international-plaza-hotel/>

The inspiring message for this year’s Educational Forum is *Imagine a Cure – Seeds of Hope*. We are pleased to have Dr. Bruce Cheson of Georgetown University as our keynote speaker for the Friday evening Welcome Dinner. Our agenda topics and speakers include the following:

- Hematology 101 – Dr. Rachid Baz, Moffitt Cancer Center
- Indications for treatment – Dr. Robert Kyle, Mayo Clinic
- Traditional therapies for WM – Dr. Christine Chen, University of Toronto, Canada
- Novel treatments for WM – Dr. Peter Martin, Weill Cornell Medical College
- Managing the side effects of treatment – Dr. Jeffrey Matous, Colorado Blood Cancer Institute

- Caring for caregivers – Mary Turney, Moffitt Cancer Center
- New developments in WM research – Dr. Irene Ghobrial, Dana-Farber Cancer Institute
- Pulling the plug on cancer cell communication – Dr. Stephen Ansell, Mayo Clinic
- The clinical trials process – Dr. Gwen Nichols, Hoffman-LaRoche
- Advances in the management of WM revealed by whole genome sequencing – Dr. Steven Treon, Dana-Farber Cancer Institute
- The “Burning Questions” about WM – Dr. Morie Gertz, Mayo Clinic

We are offering breakout sessions to present the opportunity for you to socialize and network with your fellow WMers. The Forum is also your chance to meet and ask questions of the experts in WM. As always, our popular Ask the Doctor Panel will take place on Sunday morning.

This year we are planning new ways for WMers to get together. A special event at the conclusion of this year’s Forum will be a “Scramble for WM” golf outing on Sunday afternoon. And traditionally, Saturday evening dinner at the Forum has been “on your own.” While this will not change, we are making it more convenient for you by reserving group dining space at four Bay Street restaurants close to the hotel. Details about both opportunities will be made available once you have registered for the Forum.

See our website at <http://www.iwmf.com/services/ed-forum.aspx> use the brochure enclosed in this issue of the *Torch* to register. Sign up soon and take advantage of our special early registration rate of \$199, available until April 1, 2014. We look forward to seeing you in Tampa!

SAVE THE DATE!

IWMF 2014 Educational Forum

May 16 - 18

Renaissance Tampa International Plaza Hotel

Tampa, Florida

See Enclosed Brochure to Register for the IWMF 2014 Educational Forum



A TASTE OF TAMPA

BY JULIE JAKICIC AND SARA MCKINNIE, IWmf OFFICE

As you think about coming to the 2014 Educational Forum in Tampa, Florida, on May 16-18, we hope you plan to spend a few days before and after the Forum to visit the Tampa Bay area.

You already know what a sommelier is, but what about a cicerone? This is a relatively new term for “beer expert.” Work on your beer tasting skills at the local Cigar City Brewing less than one mile from the Tampa Renaissance International Plaza Hotel, the site of the Forum. This local craft brewing company is producing popular quality beers. Stop in for a tour of the brewery or ask your bartender for a Cigar City brew while you’re in town!

Only six miles from the hotel is Tampa’s growing River Arts district, featuring numerous museums and performing arts centers: the David A. Straz, Jr., Center for the Performing Arts, the Tampa Museum of Art, the Tampa Theatre, and the Curtis Hixon Waterfront Park. With restaurants and shops nearby, you can spend an entire day appreciating nature and the arts.

You can’t come to the Tampa Bay area without seeing Florida’s natural wildlife! There are more than 20,000 plants and animals and a variety of shows to see at the Florida

Aquarium. Do you prefer to see animals in the wild? Check out the Aquarium’s Wild Dolphin Cruise and view dolphins, manatees, and native birds in their natural setting.

Head a few miles east to historic Ybor City, home to the oldest restaurant in Florida, the Columbia, which is over 100 years old and features flamenco dancing and authentic Spanish cuisine – you won’t forget the entertainment or the paella. Ybor City also has blocks of unique shops to explore.

Twenty minutes south, in St. Petersburg, the Tampa Bay Rays will be playing the Oakland Athletics on May 20 (Tuesday), May 21 (Wednesday), and May 22 (Thursday). The month of May typically has beautiful weather for a baseball game. Be sure to visit St. Petersburg’s renowned art community and the up and coming Warehouse Art District, which is home to the Salvador Dali Museum (with the world’s largest collection of Dali art), the Florida Holocaust Museum, the Museum of Fine Arts, the Dr. Carter G. Woodson African American Museum, and the St. Petersburg Museum of History. St. Pete is also famous for its beautiful beaches and spectacular sunsets.

Please join us at the Educational Forum in May and extend your stay to enjoy all that the Tampa Bay area has to offer.

Support Group Leader Workshop

May 15, 2014, 1-6:30 pm, Tampa, Florida

IWMF support group leaders will gather for a leadership workshop on the afternoon of May 15, the day prior to the Ed Forum, which will be held May 16-18. Plans are well underway and feature networking opportunities and presentations that will provide essential tools to assist leaders in planning and facilitating meetings. Guest speakers will address key topics of effective group facilitation and LLS collaboration. Leaders will share their unique success stories so all can benefit from new ideas. Hope you will join us for a fun, interactive, and informative workshop!

Marcia Klepac, Support Group Leader Coordinator
marciaklep@hotmail.com
412-421-2437

IMBRUVICA WINS FDA APPROVAL FOR LYMPHOMA

BY SUE HERMS, IWmf TRUSTEE

In a move looked upon with a growing sense of anticipation by the WM community, the U.S. Food and Drug Administration (FDA) approved ibrutinib as single agent therapy for the treatment of patients with mantle cell lymphoma who have received at least one prior therapy. Pharmacylics, Inc., made the announcement on November 13 and is now referring to its newly approved drug by the trade name Imbruvica.

Imbruvica initially received Breakthrough Therapy Designation for mantle cell lymphoma by the FDA because

of the overall response rate and duration of response seen in a Phase II study and because of the serious and life-threatening nature of the disease. Pharmacylics completed its New Drug Application in June 2013 and received approval just over four months later. Imbruvica has also received this same designation for WM and is currently in expanded Phase II trials. Hopes are increasing that Imbruvica will become the first FDA-approved drug for WM.

Imbruvica Wins FDA, cont. on page 8



Imbruvica inhibits the function of Bruton's tyrosine kinase (BTK), which is a key signaling molecule of the B-cell receptor signaling complex that plays an important role in the survival of B-cells. Inhibition of BTK blocks signals that stimulate malignant B-cells to grow and divide uncontrollably.

FDA approval for mantle cell lymphoma was based on the results of a multi-center, international, single-arm trial of 111 patients which showed an overall response rate of 65.8%, with 17% of patients achieving a complete response and 49% a partial response. The median duration of response was 17.5 months. It is important to note that an improvement in overall survival or progression-free survival has not been established, but Phase III trials are being planned to strengthen Imbruvica's case.

Safety was evaluated in the same study of 111 patients. The most common Grade 3 or 4 non-hematological adverse reactions were pneumonia, abdominal pain, atrial fibrillation, diarrhea, fatigue, and skin infections. Grade 3 or higher bleeding events were noted in 5% of patients, and Grade 3 or 4 cytopenias were reported in 41% of patients. Nine percent discontinued treatment due to adverse reactions, and 14% had adverse reactions requiring dose reduction. Warnings

and precautions listed in the prescribing information include hemorrhage, infections, myelosuppression, renal toxicity, second primary malignancies, and embryo-fetal toxicity.

The recommended dose for mantle cell lymphoma patients is 560 mg orally once a day. The yearly cost for taking Imbruvica at this dosage is estimated at about \$130,000. Pharmacyclics is offering two months of the drug for free to mantle cell patients who have trouble on the insurance reimbursement side. The company is also setting up copay assistance plans for patients who can't afford their share of the cost. Phase II studies of Imbruvica with WM patients have used a dosage of 420 mg once a day.

The most recently reported study results on ibrutinib in WM were announced in June. The initial Phase II trial enrolled 35 relapsed/refractory patients. The best overall response rate was 83%, with the decrease in bone marrow disease burden from 70% to 40% after six treatment cycles, while IgM levels were reduced from 3,190 mg/dL to 1,232 mg/dL. Red blood cell production improved with increasing levels of hematocrit from 30.8% to 39.7%. An additional 28 WM patients have now been included in this study.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMTF TRUSTEE

Bexxar Discontinued – GlaxoSmithKline announced that it will discontinue the manufacture and sale of Bexxar on February 20, 2014. Bexxar is a type of radioimmunotherapy, consisting of tositumomab and iodine 131, currently approved in the U.S. and Canada for the treatment of certain types of non-Hodgkin's lymphoma (NHL). The use of Bexxar has been extremely limited and was projected to continue to decline.

Idelalisib (CAL-101) Granted Orphan Designation in European Union – The European Union has granted "orphan designation" for the use of idelalisib (CAL-101) for lymphoplasmacytic lymphoma (LPL) patients. Idelalisib, manufactured by Gilead Sciences International, blocks the effects of an enzyme called PI3K-delta, which plays an important role in the growth, migration, and survival of B-cells.

Gilead Sciences Seeks Approval for Idelalisib (CAL-101) in the U.S. – Meanwhile, Gilead announced that its Phase III clinical trial for idelalisib in previously-treated chronic lymphocytic leukemia (CLL) patients will be stopped early because an interim analysis showed a highly statistically significant positive effect on progression-free survival. Gilead is now engaged in a dialogue with the U.S. Food and Drug Administration for a regulatory filing in CLL. A new drug application has been submitted to the FDA for idelalisib in refractory indolent non-Hodgkin's lymphoma (NHL).

European Myeloma Network Reports on Long-Term Phase II Study of BDR Therapy – A large Phase II multi-center study of the European Myeloma Network (EMN) reported long-term results from primary therapy of WM with weekly bortezomib (Velcade), low-dose dexamethasone,

and rituximab. In order to prevent IgM "flare," an initial cycle of bortezomib (1.3 mg/m² on days 1, 4, 8, and 11) was followed by weekly bortezomib (1.6 mg/m² in four cycles) and dexamethasone and rituximab in cycles 2 and 5. Fifty-nine patients were treated with this BDR regimen, and 85% responded. No patients required plasmapheresis. After follow up, median progression-free survival is 42 months, three-year duration of response for patients with at least a partial response is 70%, and three-year survival is 81%. Peripheral neuropathy occurred in 46%, but only 8% discontinued bortezomib due to neuropathy.

Novel Anti-CD20 Antibody Ublituximab to Enter Clinical Trials – TG Therapeutics Inc. announced that its monoclonal antibody ublituximab has been cleared by the U.S. Food and Drug Administration to initiate clinical trials in patients diagnosed with B-cell lymphomas. TG Therapeutics intends to recruit up to 36 patients for a Phase I dose escalation study, followed by a Phase II component of up to 77 patients. Ublituximab has also received "orphan drug" designations for both nodal and extranodal marginal zone lymphoma and for chronic lymphocytic leukemia (CLL). Ublituximab, also known as TG-1101, is a novel bioengineered antibody that targets a unique part of the CD20 surface antigen found on B-cells.

New Treanda Formulation Approved by FDA – The U.S. Food and Drug Administration has approved a new formulation of Treanda (bendamustine). The new liquid formulation eliminates the need to reconstitute the powder

Medical News Roundup, cont. on page 9



with sterile water prior to adding the medication to the diluent used for intravenous injection.

Study Reviews Differentiation between LPL and IgM Multiple Myeloma – The University of Pennsylvania and the Mayo Clinic in Rochester reviewed 15 cases of IgM-producing multiple myeloma to delineate the pathology of the disease. Of the 15 bone marrow biopsies reviewed, 40% had lymphoplasmacytoid cytology, and 80% expressed CD19, CD20, and/or CD45 surface markers. Cyclin D1 expression was present in 73% of cases and was usually associated with chromosomal translocation t(11;14). No cases expressed CD5 or had an associated CD5 positive B-cell population. CD117 was positive in 20% of cases. The study concluded that, although there is significant pathologic overlap with lymphoplasmacytic lymphoma (LPL), IgM multiple myeloma can usually be distinguished from LPL by cyclin D1 expression or t(11;14).

Canadian Acupuncture Study Reports Reduction in Peripheral Neuropathy in Multiple Myeloma – A Canadian study presented at the 10th International Conference of the Society for Integrative Oncology suggested that acupuncture may be able to reduce neuropathy associated with the use of bortezomib (Velcade) in multiple myeloma patients. These results were from a study of 27 patients who received 10 acupuncture treatments for 10 weeks (2 times/week for 2 weeks, 1 time/week for 4 weeks, and then biweekly for 4 weeks). All of the patients had grade 3 or 4 neuropathy at the beginning and had discontinued bortezomib for a median of 19 months, making spontaneous recovery not very feasible. At weeks 10 and 14, evaluations showed significant symptom reduction in neuropathy, with decreased pain, improved function, and improved objective neuropathy measurement. However, results of nerve conduction studies did not change between baseline assessment and the end of the study, and 12 serum biomarkers were unchanged, making the mechanism for symptom reduction unclear.

Combination Lenalidomide, Dexamethasone, and Rituximab Results in High Response Rates in Indolent Lymphoma – Combination treatment with lenalidomide, low-dose dexamethasone, and rituximab resulted in high response rates with durable responses in patients with rituximab-refractory indolent and mantle cell lymphoma, as reported by the University of Pennsylvania. Patients received two 28-day treatment cycles of lenalidomide (10 mg daily) and dexamethasone (8 mg once weekly) in part I of the study. During cycles 3 and 4 (part II of the study), weekly doses of rituximab were also administered. After response assessment, stable or responding patients continued to receive

lenalidomide and dexamethasone. Twenty-seven patients with follicular, mantle cell, small lymphocytic, and marginal zone lymphoma started the study; three discontinued therapy because of adverse events. For the remaining 24 patients, the overall response rate was 29% after part I and 58% after part II. The median progression-free survival was 23.7 months.

FDA Approves Gazyva (GA-101) for CLL – The U.S. Food and Drug Administration (FDA) has approved Genentech's Gazyva for patients with previously untreated chronic lymphocytic leukemia (CLL). Gazyva, also known as GA-101 or obinutuzumab, is a third-generation engineered monoclonal antibody similar to Rituxan, although it is a Type II antibody that binds more tightly to the CD20 surface antigen on B-cells. This reportedly makes it more potent and effective in the killing of B-cells than Rituxan.

The Leukemia & Lymphoma Society Partners with Valor Biotherapeutics to Develop New Therapy for Indolent Lymphoma – The Leukemia & Lymphoma Society (LLS) is committing approximately \$6 million to Valor Biotherapeutics to co-fund the completion of pre-clinical development, manufacturing, and a Phase I clinical trial for a novel fusion protein that may change the poor outcomes faced by many indolent lymphoma patients who do not respond to rituximab therapy. Valor's protein, IGN002, is produced by fusing antibodies to tumor cell-killing cytokines to create a therapeutic agent with multiple properties in a single, genetically engineered molecule. The clinical trial is anticipated to begin in late 2015.

The Leukemia & Lymphoma Society Assists with Prescription Drug Co-Pays and Health Insurance Premiums – The Leukemia & Lymphoma Society (LLS) has raised more than \$200 million in funding for its Co-Pay Assistance Program since its inception in 2007. The program provides support for prescription drug co-pays and health insurance premiums for blood cancer patients who meet certain income requirements. Patients with private insurance, Medicare beneficiaries under Medicare Part B and/or Medicare Plan D, Medicare Supplementary Health Insurance, and Medicare Advantage are eligible. To date LLS has helped approximately 36,000 patients through the co-pay program. WM patients may be eligible to participate if they meet the program requirements. Go to www.lls.org/copay or call 877-LLS-COPAY to learn more about the program.

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

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



WHAT'S IN OUR NAME?

BY ALICE RIGINOS, *TORCH* EDITOR



The name 'Torch' was a fine choice for the newsletter of the IWMF. Consider the Foundation's familiar logo reproduced on our letterhead and on our publications: A flaming torch held in the grip of a strong hand.

What is this emblem meant to convey? Since ancient times fire has represented knowledge and understanding in the presence of darkness and ignorance. Our flaming torch is a strong image conveying confidence that light will be cast on the secret ways of our cancer, for in the case of Waldenström's macroglobulinemia we seek to illuminate a particularly confounding disease. The human hand holding the torch suggests that humankind is the bearer of light, the agent of progress. Yet another ancient connotation presents itself, that of the torch that is passed from the hand of one runner to another, an unbroken succession of torchbearers until the finish line is reached. Our emblem is thus a powerful and confident image of the progress of knowledge through human initiative, through research and science, towards the goal of control and cure of Waldenström's macroglobulinemia.

The name of 'Torch' given to the newsletter implies these many aspects – confidence, illumination, understanding, responsibility shared as a team, a common goal to be accomplished. The name represents our common aspirations

as members of the IWMF. And, I might add, the name also speaks to the aims of the staff of the *Torch* in producing a publication that will address the many issues confronted by those "whose lives are affected by Waldenström's macroglobulinemia."

It has been a source of great personal satisfaction to work as editor of the IWMF *Torch* for the past five years with a team so talented and dedicated. Together we have not only given the *Torch* a new look but have also expanded its content and done our best to keep apace with the progress of current research in our reporting. All of us are volunteers working closely with the IWMF office staff to produce the quarterly *Torch*. All of us were very pleased to receive the top ranking for IWMF member services in the recent member satisfaction survey.

Moving into 2014, your *Torch* editors, writers, and correspondents are poised to keep the *Torch* advancing and improving, but now is also the time for new volunteers to join the ranks. It is time for new runners to 'take up the torch' and prepare to carry our *Torch* forward.

We are looking for volunteers with editing skills and experience in preparing articles for publication. Volunteers who like to write – especially those having the background to handle medical and research topics – are also needed. If interested, please respond to ariginos@me.com with a brief statement of pertinent experience. We are looking forward to hearing from you.

FROM IWMF-TALK

BY JACOB WEINTRAUB, M.D.

As we enter the New Year, we look back at the discussions held on IWMF-Talk to offer support, information, an attempt at education, and even amusement to our old friends and newly diagnosed members alike. Many of the topics that we touch on here have been discussed before, but there are always new members to help, different experiences with old and new treatment protocols to share, and – as the understanding of WM advances – reeducation for all of us.

TESTING OF RELATIVES:

This is far from the first time that the issue of testing for relatives of WM patients has come up. After a relative asked **Iain P** if the relative's children should be tested for WM, Iain in turn asked IWMF-Talk participants to share their opinions. Iain thought that testing of children would not be a good idea, citing the possibility of increased anxiety for those being tested and the unlikelihood of children developing WM for many years. "Let sleeping IgM sleep," he concluded.

Cathy S agreed that it is best not to raise red flags, especially because of insurance issues that may arise. Her twin sister's daughter was having blood work done, and an IgM measurement was added to her labs. Cathy's niece turned out to have an elevated IgM level, but at this point it isn't clear what that indicates.

A similar opinion was shared by **Gerald W**, who reported that Dr. Treon and a local oncologist suggested testing for Gerald's daughters. Gerald offered the option to his daughters and both declined. He agreed with their decision, noting that there is much remaining to learn about WM, that evidence is lacking to show the effect of very early treatment on survival, and that it may be difficult to obtain health or life insurance when the results of testing for WM are adverse.

IBRUTINIB AND GENETIC MARKERS:

Clearly this will be a major subject of ongoing discussion in 2014. When word came in November of ibrutinib's formal FDA approval, the announcement generated much discussion and enthusiasm on IWMF-Talk. Board Trustee **Sue Herms** noted that ibrutinib (the generic name for the drug) is to be marketed under the brand name Imbruvica. (Similarly, Rituxan is the trade name for rituximab).

Although the FDA's initial approval was for mantle cell lymphoma only, WMers participating in ibrutinib clinical trials, including **Mitch O** and **Hank S**, have been reporting their favorable results over the past months on IWMF-Talk. There is considerable anticipation about Imbruvica's eventual

From IWMF-Talk, cont. on page 11



place in the lineup of WM treatments. Here we review some of the topics from the lively discussion that the announcement generated. See also page 7 of this issue for further coverage of “where we are with ibrutinib.”

Can private individuals be tested for the MYD88 mutation? Is the success of Imbruvica dependent on the presence of the MYD88 mutation? Even though Imbruvica has FDA approval only for mantle cell lymphoma, will our physicians be able to prescribe it “off label” for WM? What will treatment with Imbruvica cost? Will Medicare cover the cost? What do we know about side effects? Such questions came in rapid succession.

Regarding testing for the MYD88 L265P mutation, **Hank S** reported that he was tested only when he had a bone marrow biopsy at Dana-Farber as part of the ibrutinib clinical trial. His understanding is that the test is not available locally. However, both **Matt** and **John E** reported that the MYD88 mutation was diagnosed from samples of pleural effusion fluid withdrawn when they were under treatment. John indicated his local oncologist could not identify any WM cells in his pleural fluid, but when they sent a sample to Dana-Farber, the fluid tested positive for the MYD88 mutation.

Is the success of Imbruvica dependent on the presence of the MYD88 mutation? **John E** cited an article showing that blocking Bruton’s tyrosine kinase (BTK) in cells with the MYD88 mutation induces cell death. However, the article does not indicate that a person must have the mutation in order for the drug to work. Furthermore, it was pointed out that the drug is effective in mantle cell lymphoma, which does not have the MYD88 mutation; therefore, the mutation does not appear to be necessary for Imbruvica to be effective.

Billie E asked if our oncologists would be able to prescribe Imbruvica off label for WM. It was reported that, once the FDA approves a medication, theoretically any physician can prescribe the medication for any condition, even off label. However, given the cost of Imbruvica and other cancer drugs, the issue of treatment will be related to insurance coverage.

Renée P posted that the cost of Imbruvica will come to \$91 per pill. If four pills are prescribed daily, the cost will be more than \$130,000 a year. This is in line with the recent trend of ever-increasing cancer drug prices. **Linda H** reported that Medicare will cover ibrutinib rather quickly based on label instructions. WM would be considered an off label use, so specific coverage will be limited at best. Medicare will need documented information about its effectiveness for WM.

As for side effects of Imbruvica, **Billie E** cited an article that listed the most common side effects as low platelets, diarrhea, neutropenia, anemia, and fatigue. **Vladimir N** contributed another troubling note. While he was on an ibrutinib clinical trial, he asked if the doctors would consider stopping the medication and observing the result. He was told, however, that there would be no break from taking ibrutinib because that may affect its subsequent efficacy.

The consensus of subsequent postings was that even though it appears that Imbruvica will need to be taken continuously and indefinitely, such a treatment regimen will be comparable to a diabetic requiring insulin every day. Most agreed that if Imbruvica continues to control our WM, the long term use would be worth it – even though at this time long term effects are not known.

Mitch O commented that even with the reported adverse effects, the glass is “more than half full.” We need to keep in perspective that all medications have the potential for side effects and that, for most people, the great promise of this drug will outweigh the potential for adverse effects.

FATIGUE:

The subject of fatigue comes up periodically. Many of us experience fatigue, and often no specific cause can be found. **Megan D** raised the question of using stimulant medication for her husband’s significant ongoing fatigue. Before trying stimulants, however, his physicians are going to check for infections that might not be readily apparent on examination or lab testing.

Ken W’s opinion is that he would be very reluctant to use stimulant medications unless he was so tired that “he had to go back to bed.” He reported such a level of fatigue after receiving bendamustine. He warned others about a “crash” in energy when the medication wears off.

Dr. Jacob Weintraub pointed out that stimulant medications in children are not prescribed to increase energy level but to help with maintaining focus. Amphetamines were prescribed in the 1950s and 1960s as diet pills and often resulted in periods of great energy and activity, followed by a major “crash” when the drug wore off. However, stimulants are now prescribed for narcolepsy, and Provigil is a new treatment prescribed for this as well as for sleep apnea. So it may be that stimulants are beneficial for some of the cancer fatigue that many of us experience in varying degrees. However, as noted in other situations, insurance coverage could be a problem.

A WM PATIENT’S DREAM:

On a lighter note, **Jan H** reported a dream related to WM. In her dream, her pet’s veterinarian called and said she had scheduled Jan for a bone marrow biopsy. It would be painless and would be done at the local Sears store. The veterinarian intimated that it is a little known secret that BMBs are performed at Sears. And it would only cost \$40. Jan got in her car, but then woke up from her dream.

The dream did generate some discussion in jest about BMB drills, including further comments about what tools Sears does carry and other suggestions for stores that might give better discounts on drills. **John E** asked about a special bone marrow biopsy drill, which does exist. However, **Hank S** reported a prior post relating to the OnControl drill, which is supposed to be less painful. No one on IWMF-Talk reported experience with this drill. The conclusion was that the costs of performing a BMB with OnControl were, for some reason, more expensive compared to the standard BMB.

In the end, regardless of whether BMBs are done by a special drill or at Sears (!), the BMB continues to be the standard method of assessing the status of disease.

TRAVEL:

The issue of travel for a person with a compromised immune system has produced a variety of opinions over the years.

Mike asked about travel insurance. He has just completed his first chemo and is thinking about traveling to South Africa to a private reserve, with the possibility of easy access to a major population center for any medical need. **Larry H** reported



that he traveled internationally last year during a treatment course and again this year while on Rituxan maintenance. He was able to purchase travel insurance that did not specifically preclude any preexisting conditions. However, Larry did obtain a letter from his oncologist stating that his health was fine for travel. That way, even if he had to cancel his travel for some unforeseen problem, he had at least some proof that he was cleared for travel by his doctor at the time of booking.

A broader comment by **Iain P** suggested checking which infectious diseases have been documented in the countries where a person wishes to travel. The World Health Organization website, www.who.int, has information about international conditions. Iain also raised the issue of immunizations for some of the more exotic diseases not usually encountered in developed countries. He reminded us that some immunizations are live virus vaccines that are contraindicated in patients with compromised immune systems, for example WMers. Iain's family did have a problem with intestinal infection while traveling in 2010, but he felt that the situation was related to hotel food and not any documented exotic infection.

Dr. Tom Hoffmann observed that many areas in Africa require no additional vaccinations or malarial medications. Other areas require vaccinations that are not live viruses and can be taken by WMers. His recommendation is to avoid any areas that require live virus vaccinations for endemic diseases.

Gayle reported traveling to Turkey while being treated, then to Israel. She took her cold medications and antibiotics and felt well equipped for what she might encounter. Gail's main problem during her trips, during and after treatment, was fatigue. However, this has not discouraged her from planning future travel.

Other members reported a variety of travels and cruises over the years to Africa and other countries. **Julie** did advise some caution, reporting that when her husband was in France he contracted leishmaniasis because of his compromised immune system, and it took a very long time to be diagnosed and treated. Even though this probably is a rare occurrence, it should be considered when traveling.

Finally, a word from **Dr. Guy Sherwood**, our Vice President for Research: take precautions, even when staying in "safe" areas (within in the U.S., for example) and check the CDC (Centers for Disease Control) website, www.cdc.gov, for a lot of very good information about traveling precautions. Also, be sure to check with your doctor about necessary immunizations and other advance preparations.

Other subjects recently under discussion included the use of IVIG, amyloidosis, transformation of WM to other lymphomas, and many more. Everyone is welcome to join IWMF-Talk. Contributions to the topic of the day are encouraged! And you will find that reading the posts of others can be very helpful.

Do take every precaution necessary and stay healthy in 2014!

TO SCREEN OR NOT TO SCREEN? THAT IS THE QUESTION

BY GUY SHERWOOD, M.D., VICE PRESIDENT FOR RESEARCH

With the recent strides made towards understanding the genetic basis of Waldenström's macroglobulinemia, many patients (perhaps you are among them) are wondering if their family members, children included, should be tested for the MYD88 mutation that is found in a high percentage of WM patients. Or, when a diagnosis of WM is established, some patients may think that they should be tested for the CXCR4 mutation, whose presence may be predictive of especially aggressive disease.

Let's stop for a moment to consider medical screening and its possible impact in the question of a cancer diagnosis.

Medical screening is a preventative health strategy used to identify an unrecognized disease in patients who have no outward evidence of signs and symptoms of body dysfunction or illness. Medical screening tests are usually administered to patients who may be at high risk for certain adverse health outcomes. The screening strategy is designed to detect disease status early on, which in turn enables speedier intervention and treatment. The principal aim of screening is to reduce overall morbidity (suffering) and mortality (death) from a specific disease.

Patients in general tend to be passionate about medical screening tests, particularly cancer screening tests. What

could be wrong about detecting a life-threatening disease at a very early stage?

It is true that a diagnosis and treatment of cancer at an early stage will help in some cases, such as Pap smears that reduce deaths from cervical cancer and colonoscopy screening for early detection of colorectal cancer. However, the data are far less conclusive for the majority of other types of cancer screening.

Not all screening tests have been shown to benefit the patient who is screened. There are criteria which need to be applied to identify which screening tests are of benefit: the disease has to be an important health problem in a given population; the available screening test for the disease must be safe and acceptable to the patient; the screening test itself must be of high quality (high specificity and sensitivity); the natural history of the disease, including the latency period, must be well understood; the screening test must be able to detect the disease before a critical point; and, finally, a treatment for the disease must be available that is neither too risky or toxic and is more effective when started earlier in the course of the disease.

We've all likely had screening tests, and we certainly are very likely to have more of them, but there is a lot of

To Screen or Not, cont. on page 13



misinformation and misunderstanding about what screening tests can and cannot do. Despite all the wondrous advances in medicine, no screening test is foolproof or can guarantee the best treatment.

How can anybody forget the passionate discourse, not always pleasant, that erupted in 2011 when the United States Preventive Services Task Force (USPSTF), an independent panel of experts in preventative and evidence-based medicine, recommended that doctors stop using the PSA (prostate specific antigen) test to screen healthy men for prostate cancer? How many remember the outcry in 2009 when the USPSTF issued a very controversial recommendation against “routine” (that is, not high risk) screening mammography among women aged 40 to 49 years?

The FDA (Federal Drug Agency) approved the PSA test in the mid 1980s to monitor patients with diagnosed prostate cancer and later in the mid 1990s to screen healthy men. Approval to proceed to treatment was granted on the basis of this test before researchers had determined whether testing improved survival – without evidence that it provided benefit and without accurate scientific assessment of the potential harm. To date researchers have never demonstrated that treatment based on PSA testing of healthy men reduces the overall number of deaths. Out of a million men treated for prostate cancer between 1986 and 2005, 5000 (one in 200) died from surgery, up to as many as 30,000 had a heart attack or heart problems after surgery, and up to 300,000 became impotent, or incontinent, or both. Many experts have stated that there appears to be insufficient evidence that treating asymptomatic prostate cancer patients extends their lives.

PSA screening “doubters” also argued that the potential harms made it unethical to recommend screening without scientific evidence of meaningful benefits. Advocates of PSA screening (e.g. American Cancer Society, American Urological Association, American College of Radiology) dismissed the concerns about harms and warned that waiting for definitive evidence would result in lives lost.

In 2009 the USPSTF recommended against routine mammograms for women under age 50, a recommendation that drew fierce protests from many women’s groups, radiologists, and politicians. The chances of a woman dying from breast cancer over the next fifteen years were 0.48% if she did not receive a mammogram and 0.38% if she did. Despite the harms identified in screening low risk women for breast cancer (over-diagnosis, misdiagnosis, anxiety, potential risks from painful “downstream” diagnostic procedures), the USPSTF quickly learned from the 2009 mammography controversy that recommending physicians to abandon testing of certain populations and instead to encourage individual decision-making could be easily misread as a recommendation against screening.

In the world of Waldenstrom’s macroglobulinemia we have a number of potential screening tests. Asymptomatic patients can be routinely screened for WM by having yearly physical exams and blood draws including serum protein electrophoresis, flow cytometry, and even bone

marrow biopsies. One could certainly propose that patients, particularly “high risk” patients (the so called “familial WM” or MGUS patients), be tested for the MYD88 mutation or the CXCR4 mutation. But we need to step back from all this and ask ourselves if early screening for WM in asymptomatic individuals would change the outcome for anyone found to have WM, particularly when one of the core principles in WM treatment is not to treat too early (watch and wait) or not to over-treat (which sadly happens far too frequently).

Early detection does not automatically lead to better care, as much as we’d like to believe it. The medical screening debate is essentially how to balance potential harms versus potential benefits. Harms from screening exist; the burden of these harms can be challenged but their existence cannot. Screening can produce complications (for example bleeding or infections from biopsies), anxiety over abnormal results, a surge of expensive follow-up costs and treatments, or, even worse, the workup and treatment of a disease that poses little threat to a patient’s overall health.

Patients and medical experts are taking a closer look at all medical interventions, not just cancer screening. Concern is growing because physicians recognize the risks and side effects of intervention. The American College of Radiology, as an example, is leading a campaign to reduce the unnecessary exposure to radiation from CT (computed tomography) scans and other radiology tests that are estimated to cause up to 29,000 cancers a year in the USA.

One cannot predict whether greater awareness of harms will dampen patients’ enthusiasm for questionable screening tests. More realistically, in these days of fierce budget debates and cutbacks, resource limitations will intervene; wasteful screening practices will become increasingly unaffordable in an economy already struggling mightily with soaring health care costs. Nonetheless, our first concern should be to demonstrate that screening is of net benefit to public health. Harms must be considered independently of costs, otherwise concerns about the safety of medical screening tests will continue to be mistaken for thriftiness.

In conclusion, screening tests can be very helpful and necessary but they can also at times do more harm than good. The USPSTF offers sound recommendations for screening based on the latest available scientific evidence (these can be found at www.uspreventiveservicestaskforce.org/recommendations).

There is no easy “one size fits all” magic formula. There are many arguments to be made for and against medical screening tests. The decision remains a highly personal one that inevitably relies on the patient’s “comfort zone.” However, patients must absolutely be well informed of all the potential consequences either choice can bring.

Lastly, more information is not always a good thing, and perhaps there are times when it’s just “better not to know.” This is something to think about as we each struggle with management of our own individual case of Waldenstrom’s, a disease that varies widely from patient to patient, or as we consider the futures of our family members.



COOKS' HAPPY HOUR

BY PENNI WISNER

We have now put the holiday season and its celebratory feasting behind us. But for those of us who love food and cooking, the question remains: What to eat now? Here's a suggestion: Carrots.

"Oh, so boring" you think. But bear with me. Have you noticed interesting menu entries that mention carrots? Now think about cooked carrots (not the boiled carrots of my childhood no matter that I loved them) and how sweet they are. Plus they come with almost no calories and many benefits including antioxidant, cardiovascular, and anticancer. A quick way to meet your New Years resolution to cook and eat more healthfully (That was your top priority, right?) is to steam your carrots instead of boiling them. Microwaving them is another good option.

But first, here's an idea for a spread or dip: Preheat the oven to 375°F. Scrub and peel (optional) some juicy carrots. Toss them with a little oil, some whole, unpeeled garlic cloves, and a sprig or two of fresh rosemary. Put them in a baking dish or on a baking sheet, cover, and roast until the carrots are tender, perhaps 20 to 30 minutes or more depending on their size. Uncover and continue to roast until the carrots begin to brown. The caramelization will add a lot of flavor to your dip. To make the roasting go more quickly, cut the carrots into smaller pieces. When very tender, puree the carrots, rosemary leaves, and peeled garlic with a can of drained (taste the liquid, and if good, save it to use to thin your dip), organic white beans (or home-cooked beans), a little fresh or dried thyme, the zest and juice of a small orange or lemon, a splash of olive oil, and salt and freshly ground pepper to taste. If the mixture seems too thick, thin with a little of the liquid from the can or with water.

Making chips, usually a health no-no, can be okay and even better than that when baked instead of fried and when made from vegetables such as carrots. I think I have spoken previously about kale chips. If not, mea culpa, but you can find them packaged now. (Although I confess that buying a packet of crumbled, not very fresh-tasting kale chips was less than rewarding.) Parsnip chips might be my favorite and carrot chips are fun. And pretty, too. Meanwhile, this is the method, so experiment away on the vegetable. The only tip to keep in mind is to try to avoid overlapping your chips on the baking sheet. (This is a particular challenge with kale, less so with non-leafy veggies.) Carrot chips: Preheat the oven to 375°F. Peel several firm, juicy carrots. Cut them into very thin rounds on a mandoline, or into long, very thin strips with a vegetable peeler. Toss the carrots with a little oil – organic canola oil, olive oil, or even coconut oil – and salt and freshly ground pepper. Add other spices if you like: cinnamon and/or coriander for a sweet-seeming chip or cumin and/or cayenne (a tiny pinch!) for a spicy version. Spread the carrots on baking sheets making sure the pieces do not overlap and bake about 5 minutes. Rotate the pan(s) and return to the oven until the edges begin to lightly brown, about another 5 minutes. Cool the chips on a rack. As they cool, they will get crisper. Be careful not to overcook. Taste and season again with salt and pepper, if you like. Store in an airtight tin for up to several days.

Now I want to describe a dish I learned last year and nothing this year has come close to matching it: a roasted carrot and avocado salad adapted from ABC Kitchen in New York. The recipe appeared in a story about carrots by Florence Fabricant for *The New York Times*. The carrots are roasted just as for the dip, above, but a halved orange and a halved lemon are added to the baking dish to roast along with the carrots. If you have never roasted citrus, it may become your new favorite flavor. The spicing is very simple: a pinch of chile flake, some thyme, and some cumin. The completed salad is to be served sprinkled with sprouts (and we all know that sprouts are "the little engines that could" as far as nutrition is concerned), a scattering of pumpkin seeds, and dollops of sour cream. I usually forget all these welcome niceties and never miss them but the sprouts and pumpkin seeds would add a fresh crunch. You could use lettuce, or watercress, or arugula.

So forthwith: Preheat the oven to 400°F. Chop several fat cloves of garlic and mix them in a small bowl with a teaspoon each of crushed cumin seed and chopped fresh thyme, 1/4 teaspoon chili flakes, 1 1/2 teaspoons kosher salt, 3/4 teaspoon freshly ground pepper, 1 tablespoon red wine vinegar, and 2 tablespoons olive oil. Pile 1 pound of medium or small carrots into a baking dish and drizzle the spice mix over them. Toss well to combine. Halve an orange and a lemon and place them, cut sides down, on top of the carrots. Cover well and roast until the carrots are nearly tender, about 30 to 40 minutes. Remove the cover and continue to roast until the citrus and carrots have browned and the carrots are completely tender. It might take an hour, depending on the size of the carrots. (The roasting has always taken longer than the recipe stated, and I have only had luck when I've covered the baking dish. This way the carrots braise in the oven and cook more evenly.) When tender, transfer the carrots to a serving dish. Using tongs, squeeze the juice from the citrus into the baking dish and discard the shells. Add another 2 tablespoons olive oil and mix well. Slice a ripe avocado and arrange the slices over the carrots. Drizzle the dressing over all. Add a scattering of pumpkin seeds and sprouts if you wish. Serve with crusty bread to soak up the juices.

I made this salad for a pre-Thanksgiving lunch last year and wanted to end the day right there. It was that good. New Year's resolutions do not need to hurt. I will leave you with one last carrot idea, this one from a San Francisco restaurant – use the freshest, youngest carrot fronds to make a little pesto: puree a packed cup of carrot tops with a fat garlic clove, salt and pepper to taste, the juice of 1/2 lemon, a pinch lemon zest, and a half cup or so of good olive oil. Use this to top roasted carrots, or to stir into hummus, or as a drizzle atop the carrot-white bean spread. Happy New Year!

Our motto: Eat Well to Stay Well

*Combating cancer? Calories? Cholesterol?
Consider the common carrot, crisp, crunchy, and colorful.
Clever cookery can change its character,
creating...chips...dips...and salads!*



CAREGIVERS ARE ALSO SURVIVORS

The diagnosis of cancer plunges a new patient into a state of confusion and fear concerning the immediate threat and the prospect of survival. The newly diagnosed WM patient may need therapy right away and so must make treatment decisions without fully comprehending the differences among the available options, or he or she may be placed on a watch and wait status and then will worry that this approach is not sufficiently pro-active in confronting the cancer diagnosis. In either case it becomes clear to each new patient from the outset that there are difficult and unpredictable challenges ahead for the rest of one's life, however long that may be. Many of us, probably most of us, will not meet such challenges alone because the same vortex of anxiety and uncertainty will draw in persons who are close and dear to us, be they family or faithful friends or others whom we meet as strangers offering kindness and support. We come to depend on these caregivers who are willing to give more than we can ever return in exchange for their services, support, and solace.

Nearly every issue of the *Torch* contains personal accounts of WM survivors who have been treated successfully and are living for many years. In each of these success stories there is surely a person in the role of caregiver (and perhaps many are in this role for each survivor), yet we have not given

caregivers the coverage in the *Torch* that they deserve as those also "affected by Waldenström's macroglobulinemia." In this issue we begin to correct this oversight by reflecting on the importance of the role of caregiver and by giving voice to caregivers and hearing firsthand of their own challenges.

The two caregivers who share their experiences are women who have become carers for their spouses. Since the majority of those diagnosed with WM are male, the wife-as-caregiver is not an uncommon role among WM couples. Our contributors Sue Drake and Megan Davey also speak for yet another segment of the WM population that the *Torch* seems to pass by all too often. This overlooked segment is comprised of "younger WMers" – those diagnosed well under the age of 60. Younger WMers are not concerned with spending their senior years integrating the demands of an indolent cancer into their lifestyle. Younger WMers find their lives upended in mid-career at a time when they may also have children at home. As uncertainty and fear spread to all members of the family, the combined role of the caring parent and the caring spouse grows daunting. Both Sue and Megan are active in their chosen professions and are raising school-age children. Their own words vividly record the dramatic changes in their lives following the diagnosis of WM for their husbands.

WHEN CANCER CAME INTO OUR HOME

BY MEGAN DAVEY

Davey Studios is the commercial venture of Megan Davey and her husband Mark, an artist who specializes in mural painting. Debilitating neuropathy led to Mark's diagnosis of WM, and he has been subjected to many rounds of plasmapheresis and a number of demanding treatments without great success. Megan's own words portray the impact of WM on the family as she tells how each of her young children reacted to their father's illness. Readers will admire the pluck and spunk of Hannah Davey who, in effect, created her own support group when she felt the need to be able to talk frankly about her father's disease with her own contemporaries.

I have become a fortress, guarding my fears from the one I consider my best friend. I hide my worries and exhaustion, or so I tell myself, until I see a reflection in the mirror and then I think, "Who is that woman who has aged so?" Her hair is gray too soon, her eyes dark, her face set with lines that were not there a short time ago.

As a child I had a keen sense of death and loss. I lost a grandfather, to whom I was very close, at the age of six. To me he was a rock, and I still cherish the quiet times I had with him. He showed me how the "great" typewriter put his thoughts into words that became sermons. When a bird he was caring for was killed, he shared with me the importance

of taking care of the smallest of creatures. And so, not surprisingly, I was already aware of the gift each day holds. Yet to hear a time frame for the one who carries your heart, the father of your children...that changes everything.



The Davey children shortly before their father, Mark Davey, was diagnosed with WM.

Caregivers are Also Survivors, cont. on page 16



I find myself constantly researching for the latest new drugs, the best recipes, or the vitamins that may hold the key. I research, read, study, compare, and search. I am the first awake, and the last to bed. I keep the house quiet when needed. I complete data charts, make appointments, and e-mail for test results. Ever vigilant for signs that anything may be amiss, I watch for energy levels, unusual skin issues. I cope with his forgetfulness and wear patience like armor. I try to be aware of his mood, and I am a barrier between his mood swings and the children.

The children. This is the hardest part for both of us. Our children were six, ten, and thirteen when Mark was diagnosed, and each child has had to deal with this in his or her own way. Our youngest, six-year old Stella, was not too worried in the beginning. She only knew Daddy didn't feel well, and her way of showing affection was to cover him in stickers. Always. Such a shy, tender heart – and Mark was never without Stella's stickers!

Once when he and I travelled to Mayo Clinic and he was in a wheelchair due to peripheral neuropathy, he realized he had lost a sticker given to him by Stella. I had to run up and down the sidewalk until I finally spotted the sticker in the street. I saw that finding the sticker and returning it was of the greatest importance to him.

Since that diagnosis three and a half years ago, Stella has been a source of a "child's guiding light." She has since put the dots together and realized that her Dad is dealing with an illness that is potentially fatal. She has dealt with anger towards God for allowing her Daddy to have cancer, and I have shown her examples of others who wrestle with their beliefs and assured her that this is perfectly normal and healthy. I have never felt that I should tell the children more than they need to know. The most important thing is that they know they can share their concerns and worries with us. I would not want them to try and carry this alone.

Our middle child, Hannah, was eleven when we came home and told the children that Daddy had cancer. She was the first one to run over and hug him, yet she never wanted to talk about it. She would still rather not discuss her Daddy's illness, but I know she thinks about it as I come across her drawings and writings. About two years ago she came to me with a seemingly easy request to fulfill: "Please, Mom, I would like to find a group of kids that I can talk with." She had adults in her life she could speak to but no kids her age to empathize with her. So I began searching, and to my surprise I found **not one** group in the entire Memphis area for children with parents who have cancer.

There are groups for parents of children with cancer, siblings with cancer, and children who have lost their parents. But there was no group for a child who is living with the potential loss of a parent, a loving parent who provides such an important sense of security in a child's world.

Hannah then took it upon herself to start a group at her middle school. At first her request to form the group was rejected, but she wrote a moving letter to the principal and the school counselor, and soon they had a group!

One of the first things I recall her saying after the initial meeting was, "Other families tried juicers, too!" It was this connection that made the children feel that their families were separate from others. And this sense of being separate joined them together.

Since then several students have lost parents, bringing new issues to deal with and a realization that not all cancers are curable. The group has continued into high school. One of the boys in the class still meets with the group even though he lost his father. He told Hannah that he feels like he can speak freely about the struggle his family is facing now and about his worries for his Mom.



Megan and Mark with children and turkey at Thanksgiving 2013.

Creating this group, and filling not only her needs but also the needs of others, has been a large part of Hannah's constant healing. Long-term illness is like having a scab that doesn't have a chance to heal. It is constantly getting "scratched," and just when you start to see the new skin healing underneath, something happens and the wound is fresh again. Our hearts are in a fluid state of healing, breaking, and healing. And breaking.

Which brings me to our only son, our oldest, Grant, only thirteen when his Dad was diagnosed. That first night, after everyone had gone to bed, I sat next to him as he asked me, "Mom, is it curable?" I had thought I would have a little time before he asked me the hard questions, and I was not prepared with any comforting answers as I was still reeling from hearing "three to five years."

I took a deep breath and silently asked God for guidance. I



received the answer I still cling to today. *No man knows our time here on earth. All lives hang by a thread, and we must live every day as if it is our first and last.* I was honest and shared with Grant that the doctors did not yet have a cure for Daddy's cancer, but we were blessed with time, and that is more than some. We were blessed to have our eyes opened to see the true gift in every day. But he cried, and I cried, and we have all had moments of grief since.

Which brings me to myself, I guess. Here are a few things I have noticed. Rare is the person who asks, "How is the caregiver doing?" By the nature of his illness we seem to revolve around Mark. It seems that when a wife is diagnosed with cancer, people jump to help with the children, the cooking, the housekeeping, and even with things like make-overs. When the husband is diagnosed with cancer, few ask about car maintenance, yard work, house repairs, or any of the tasks already noted. Often the wife will not bring these up as they add stress for her husband, the patient. Possibly this is because a wife fears her husband will attempt to do something that is risky for his condition, or because men do not like to be seen as needing help. Or perhaps women are just expected to take on more, as they typically do.

The grieving process begins at the word *cancer*, and I don't know that it ever ends. You grieve for your life before the

diagnosis, you grieve for the loss of the life before multiple doctors, chemos, waiting rooms. You grieve for a life without so much pain and fear.

So if you should ask how we, the caregivers, are doing, and we hesitate, it is because that answer can change so quickly. And, honestly, some days we just don't know. At one moment things can seem fine, and for that moment we may forget, but in a split second it can change. A blood test can come back with bad news, a low white count can mean cancelled plans or, worse, back to chemo.

The children learn quickly about germs and watch their friends for any suspicious sneezing. Other children and parents may not realize how stressful this is for a child. But **this** child **knows** how sick his parent will be if he brings home that virus. On the other hand, these children learn to love deeply. They see the value in spending time together. They are wiser than their peers and empathetic as well.

Everything in life holds a balance, and we naturally search for the balance in the cancer diagnosis too. We have to. It is our number one job as caregiver, to see that our spouse, and our children, and sometimes even ourselves, find the balance. The balance to survive.

CARING BEYOND SURVIVAL

BY SUE DRAKE

Sue Drake is wife and caregiver to Jeff Drake, who was diagnosed with WM on May 9, 2012, at the age of 43. She teaches middle school English and science, while Jeff is the Network Infrastructure Manager at a local community college. Sue enjoys reading, writing, and jogging and considers coffee and dark chocolate as two of the major food groups. When Jeff is not talking to computers, he manages to be an avid outdoorsman, musician, and vocalist.



Sue and Jeff Drake
with their boys.

You can use your terminology of choice – *journey, battle, path, survivor, sojourner*. You can make it sound more innocuous by calling it *indolent* and *treatable*. WM is still cancer and there is nothing indolent about its entrance into anyone's life.

As full-time teacher, mother of two boys (ages 10 and 12), and active volunteer at my church, my life

was pleasantly busy. When my oldest was diagnosed with dyslexia and I became a full-time tutor as well, the "busy-

factor" increased. When my husband and best friend, Jeff, was diagnosed with WM at age 43, my life became reduced to putting one foot in front of the other. When three first-line treatments failed, I seriously began to consider what it would be like to raise our children without him. I wasn't really living at all...just surviving between the sunrises and sunsets.

With Jeff currently on the ibrutinib trial, we are no longer infusion- or plasmapheresis-dependent. During the past few months I have been able to breathe and take a step back from the picture of what had been our life for the past year. Here are a few truths as a caregiver that I learned from the classroom of WM.

1. I learned how to say yes.

Declining help had more to do with my pride than anything else. I had to get over the fact that Wonder Woman had lost her cape, the invisible jet had crashed, and my body wouldn't fit into that outfit. I needed help, and it was selfish of me to deny others the only avenue they had to reach out to my family.

2. I learned how to say no.

I want everyone around me to be happy (you can quit laughing now). When asked to volunteer for

Caregivers are Also Survivors, cont. on page 20

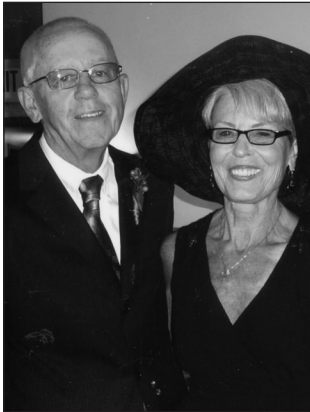


CREATIVE GIVING – WHAT'S *YOUR* IDEA?

BY MARILYN BAGEL

Though the official year-end giving season has come and gone, we hope you'll think of the IWMF year round because, month in and month out, both WM and our efforts are unrelenting, and no amount is too small. That's why we are taking this opportunity to inaugurate a regular newsletter feature that focuses on what our members are doing to contribute to

the IWMF in ways that are comfortable for them.



Ken and Marcia Wierda

Meet Marcia and Ken Wierda. Marcia is one of a family of six children and was born and raised in Bauer, Michigan, where she has been a lifelong resident. Her strong work ethic began early on. As a youngster, she picked strawberries, beans, and blueberries for local farmers. In 1962 Marcia graduated from Calvin College in Grand Rapids, Michigan, with a degree in education and later

earned her Masters Degree from Michigan State University. She taught in the Hudsonville Public School system for more than twenty-three years.

Her husband Ken, also one of six children, went to a two-room elementary school. He ultimately graduated from Davenport Business College. Fortunately, back in the day being able to work their way through school with full-time summer jobs and one day a week during the school year meant no student loans to pay off after graduation. In fact, it was at Marcia's summer waitressing job at the Rainbow Grill in Grandville, Michigan, where the couple met. Ken would stop on his commute between Holland and Grand Rapids. They married in 1969.

After working for a Mack Truck distributor and spending six years in the U.S. Army Reserves, Ken started his own heavy-duty truck parts replacement business in 1976 with a partner. Today it has thirty full-time employees, including sons Tim and Andy.

Marcia and Ken were always philanthropically focused, tithing to their church early on and actively involved in their community. When Ken turned 50 in 1991, in appreciation of his loving wife, two fine sons, good business conditions, and some accumulated wealth, he increased their charity contributions to 25% of their income, initially for four years and then each year ever since. Most grateful for their blessings, they are hopeful that others can consider doing the same. With Marcia's diagnosis in 2003 of Waldenstrom's,

their philanthropy took on an especially personal significance.

Here are some other ways the Wierdas continue to stream funds to the IWMF.

Perhaps these will give you some bright ideas.

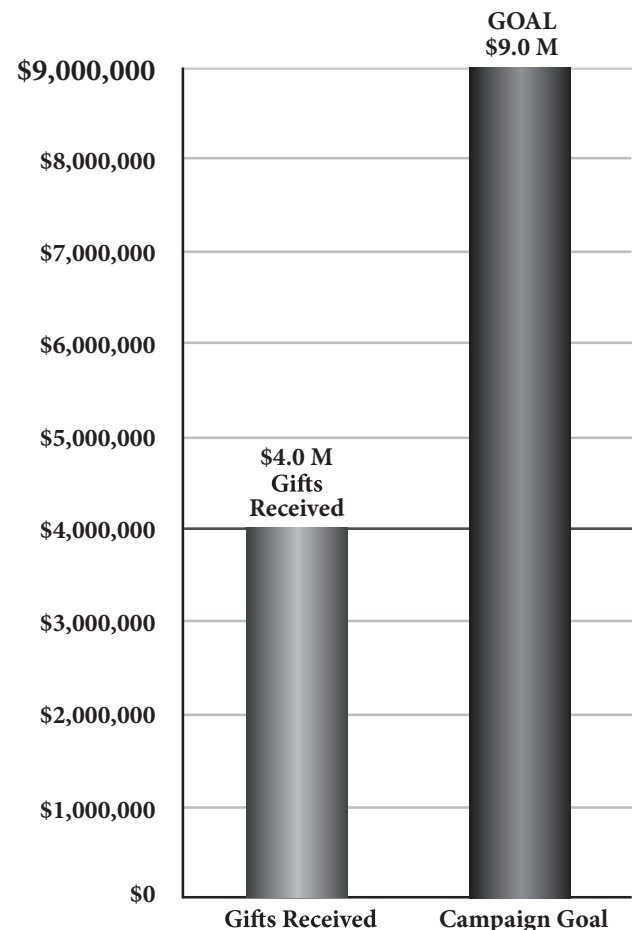


In addition to cash contributions and pledges, the Wierdas recognize special occasions of friends and relatives by contributing tribute gifts in their names to the IWMF. Likewise, they celebrate the memory of those who have passed.



For birthdays, anniversaries, and holidays, Marcia and Ken told their family and friends that the greatest gift they could receive is a card from the IWMF saying that contributions celebrating these occasions have been made in their names. That spirit has

Imagine a Cure Campaign Progress Report as of September 30, 2013



Creative Giving, cont. on page 19



spilled over to other family members. For son Andy's second marriage, his wife wanted a big wedding, and they requested contributions to IWMF in lieu of wedding gifts they did not really need.



Marcia and Ken have owned a condo in Florida ever since their kids were high school age and actively involved in tennis. Since Marcia's diagnosis, they regularly donate a week's stay to several church and parochial school auctions to benefit those institutions. They also offer their condo to friends and family at no charge with the understanding that they send a contribution to the IWMF. Every November, Marcia treats her sister and two friends to a plane trip to the condo. In return they make contributions.

Here's what you can do starting right now

The goal of this Creative Giving column is to inspire everyone to get involved on some level throughout the year.



If you're in the financial position to do so, consider donating a percentage of your IRA rollover or life insurance, or commit to contributing a portion of your Social Security payment once each quarter.



When you establish a matching fund, it always results in greater giving to the IWMF. You can call the IWMF for more information and to arrange a matching fund in any amount.



Sponsor a fundraising party around a sport such as bowling, golf, or tennis and have participants contribute to the IWMF as their fee.



Volunteer your time to the IWMF in some capacity. Call the IWMF office in Sarasota at 941-927-4963 and ask how you can help.



Have a yard sale to benefit the IWMF.



Many WM patients are nearing or beyond normal retirement age. However if you are a healthy spouse and don't need to be a full-time caregiver, consider continuing working and donate a portion of your income to the IWMF. Ken is 72 and works about 80% of the time, which helps make possible what they do.



Create your own 'IWMF Collection Jar' at home. At the end of the day, toss all your loose change in the jar. At the end of each month, count up what you have and send a check for that amount to the IWMF. It really adds up. Think of it as 'Change for Bringing Change to WM!'



Did you know that there's a search engine you can use that will result in automatically supporting the IWMF? Good Search is a Yahoo-partnered search engine using the Bing search engine. It donates 50% of its revenue, which is approximately a penny a search, to charities designated by its users. Register with Good Search and designate the IWMF as your beneficiary. Whenever you search the web, shop online, dine at participating restaurants, take surveys, and play online games, we benefit. The money comes from the search engine's advertisers. As of September 2013, the ASPCA earned more than \$50,000, Cystic Fibrosis more than \$20,000 and St. Jude Children's Research Hospital more than \$18,000. Just think what's possible for the IWMF if we all register with Good Search. Go online and sign up today. And be sure to tell your friends, relatives, and neighbors.

Please e-mail your bright ideas for Creative Giving to mbwriter2@verizon.net so that we can highlight them in future columns.

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



something I knew would throw my balance over the edge, I didn't want to risk the distasteful thought of disappointing someone. After a few of these instances, I realized that there are other people who could do these tasks just as well as I could, but as a caregiver and a parent, there is no one who can do the task of mothering my children and caring for my husband like me.

3. I learned how to prioritize.

Sometimes the dishes got left in the sink, the weeds didn't get sprayed, I ordered pizza instead of cooking, and the inside of my van looked like a dumpster had exploded. Eventually the dishes got cleaned, the weeds were executed, I managed to put spaghetti on the table, and I got a shovel for the van. But I had to let go of my tendency to obsess about the small things and enjoy the big things, like losing my shorts in a family game of Monopoly.

4. I learned to take time for myself.

And NOT feel guilty about it. I am no good to my family when I am burned out and surly. It is far better for me to drive 35 minutes to the nearest Starbucks, drink a horribly overpriced double-shot latte, listen to the small talk and feel "normal" than if I had spent that time doing something I thought had to be completed right then. Sometimes removing myself from the situation, even for a brief respite, was enough to keep me going for days. Recharging my batteries benefited my family just as much as it benefited me.

5. I learned that helping others in small ways is a great way to keep my focus outward.

Cancer and chronic health issues had pushed me into a narrow focus indeed. I was a Google addict and knew more about WM than what was going on next door. Running a portion of the meal I had just prepared to my neighbor whose husband was suffering from pancreatic cancer gave me a reality check. There are other folks, even in a 5-mile radius of my house, who are also suffering. We are not

alone. Journaling on *CaringBridge* has also allowed me to share in the "bigger picture" and sometimes even helps other people in ways I never imagined.

6. I learned that I am not in control.

And that is OK. Consider Disney's Aladdin and the genie's boisterous proclamation: "PHENOMENAL COSMIC POWERS...and an itty-bitty living space." Change the wording a bit and it describes where I was: "PHENOMENAL COSMIC BURDENS...and an itty-bitty coping capacity." While my faith in God has always been a prominent part of my life, I realized that I operated under the notion that God needed my help in running the universe. Stripped of that ridiculous notion by circumstances beyond my control, I felt a bit lost but also relieved. While we all do not share the same faith, we could all probably agree that we are not God. Isn't that a relief?

7. I have learned not to underestimate the deep effects of cancer and chronic illnesses on the human heart and soul.

It is not easy to balance my desire to dismiss the inconsequential 30 point rise in an IgM reading while also to be fully supportive of my husband who fears an upward trend. To dismiss the fear would be just as damaging as feeding the fear. While I may be holding down the fort, he is the one whose bodily fort is being bombarded by an enemy invader. I need to be respectful when he doesn't want to talk about it and support him when he has moments of fear (or whatever range of emotions this ride can cause). Even those who weather this storm well are still battered and need to know their caregivers are a safe harbor when they need it.

Yes, it's cancer. Ugly, fear inducing, and costly in so many ways.

But we are choosing to actively live with it each day rather than waiting to die with it or from it. Each day is too precious to be surrendered to a mindless disease. Our hope and prayer is that you will join us in exploring the fullness of life between each sunrise and sunset.



SUPPORT FOR THE DADS

The previous article touches on the impact of a parent's cancer diagnosis on young children and recounts the way one child found to manage her concern and anxiety. Continuing the

theme of WM within the family, the following two examples illustrate special ways that "Wally fathers" are supported by their sons.

A 5K COSTUME FUN RUN FOR WALDENSTROM'S MACROGLOBULINEMIA

BY SECRET WALLY AND SON

One high school senior, the son of a WM survivor, recently came up with a novel idea for his "senior project" that was a requirement for graduation – a project that would show support for his WMer-Dad by raising awareness of WM and fundraising for the IWMF. The innovative project was to coordinate a 5K/1K "costume run," with 50% of the proceeds to go to the IWMF. Speaking in his own words, the teen-age coordinator describes how his father's illness inspired him to find a way to spread awareness of WM and to raise money for the IWMF Research Fund.

Having a parent who is dealing with WM is not an easy situation for anyone. During all of the days I spent in the hospital with my father while he was undergoing treatments, there were times when all I could do was to think. I always thought about what was going to happen next. Will the treatments help or will he just get worse? How much longer will he have to push through this to survive it? After my father fought WM back into remission, I realized that I wanted to do something to spread the word about this little-known cancer. In October of 2013, I held a costume 5K run for my high school senior project. The purpose of this run was to raise money to develop better drugs and, hopefully, one

day a cure for WM. My 5K helped spread the word about WM and raised quite a bit of money. I can only hope that spreading knowledge of WM will lead more people to donate more to find a cure.

A total of \$900 was raised for the IWMF and the event was so successful that the school plans to adopt it as an annual event, with a different senior taking it on as a senior project each year.

Forty runners participated in costume, and a number of spectators came incognito, including a pair of Sonny and Cher impersonators. Anyone you recognize?



Sonny and Cher were among the boosters at the 5K fun run.

A DRUMMER'S WAY TO KEEP WM AT BAY

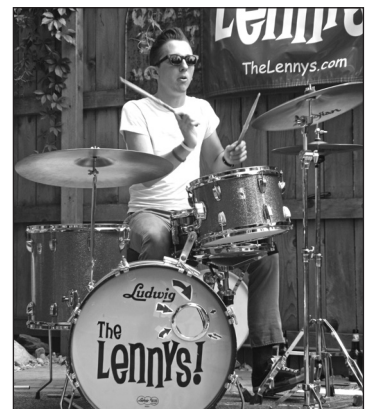
BY DON BROWN, CHICAGO AREA SUPPORT GROUP LEADER



The father-son Perrin duo. John (on the left) and Dave play together in a family rock band.

John Perrin, son of Chicago Area support group member Dave Perrin, wears the Waldenstrom's wristband continually in honor of his father, and he wears them out frequently. John plays drums with his dad in their family's rock band. He is also the drummer for a group led by a cast member of the Million Dollar Quartet. (This musical has been running for years at Chicago's Apollo Theater, based on the true story about how Elvis, Johnny Cash, Carl Perkins, and Jerry Lee Lewis came together and "jammed" at Sun Records in the 50's. Some subsequently left Sun Records for the much bigger RCA and Columbia Records).

Recently John wore his Waldenstrom's wristband and gave it a workout on the David Letterman Show when he played



John Perrin at the drums. Notice the WM wristband.

for the first three nights of "Elvis Week" as drummer in the band supporting the Elvis impersonator from the Million Dollar Quartet and others.

Don Brown is always happy to provide John Perrin with new wristbands – and a few to spare. His father Dave calls in an order when the supply runs low.



FIFTH INTERNATIONAL IWMF DOCTOR-PATIENT FORUM

LONDON: SUNDAY AUGUST 17

BY ROGER BROWN, WMUK, AND GUY SHERWOOD, IWMF

The wide world of WM comes to London in August and it's not too early to register for the Fifth International IWMF Doctor-Patient Forum to take place on Sunday, August 17, and open to WM patients, their carers, and family.

The Doctor-Patient Forum is held in conjunction with the eighth International Waldenstrom's Macroglobulinemia Workshop (IWWM8) running from Thursday, August 14, through Saturday, August 16. This international colloquium of Waldenstrom clinicians and researchers is by invitation only and is not open to patients. (Program details can be found at www.wmworkshop.org).

At Sunday's Forum, dedicated to patients and carers, specialists will reveal their latest research, treatments, and trials results. IWMF and WMUK are jointly working with Dana-Farber's Bing Center, the organizers of IWWM8, to deliver one of the

most important doctor-patient days held thus far. The location for the Forum is the Park Plaza Westminster Hotel (opposite the Houses of Parliament).

While the final program is not yet fixed, it will feature leading UK, European, and USA specialists, highlighted with keynote presentations by Dr. Steven Treon and his associates. This will be a uniquely exciting Forum with news of emerging breakthrough therapies. In addition there will be the usual favorites in this very busy day, including 'Ask the Doctor' and 'Patient Tales' displays and one-to-one meetings with experts.

The final program will be available on the IWMF and WMUK websites. Online booking will be up and running at www.wmuk.org.uk by the time you read this. There is a maximum capacity of 220. Book early and make a holiday of it!

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIAN SUPPORT GROUP

Following on from the valuable contributions made to the WM cause in Australia over the last decade by Gareth Evans and Colin Perrott, a new Australian Advisory Group was announced in July. The new Advisory Group met with WMozzies members in Sydney on 24 October to listen to their patient concerns and matters needing to be addressed. The Group also met that day with the Leukaemia Foundation of Australia on advocacy issues confronting WMozzies. Principal focus is on initiatives to enhance Australian WM best patient treatment and funding. Other areas being addressed by the Group include: organization of suitable meetings and forums for WM patients and carers as well as WM patient support activities and the website; identification of WM specialist haematologists and hospitals experienced in treating our orphan disease (IWMF has already published an Australian specialist list); facilitating financial donations to support WM research scholarships and fellowships; reviewing treatment options available to identify any shortfalls from WM world-best practice; active advocacy to assist initiatives to widen PBS (pharmaceutical benefits scheme, funded by the government) coverage to provide funding of world-best WM treatments in Australia. The initial members of the group are: **Peter Carr** (Qld), **Peter Marfleet** (Vic), **Peter Smallwood** (Qld), **David Young** (NSW), **Janelle Sullivan** (NSW), and **Andrew Warden** (NSW). Intentions are to broaden the group membership to include other states and territories.

The event of the year for WMozzies was a patient forum held in Sydney on 25 October. The keynote address was delivered by **Professor Meletios Dimopoulos** of the University of Athens, Greece. Professor Dimopoulos is also a member of the IWMF Scientific Advisory Committee and recipient of the IWMF Robert A. Kyle Award, which is given in recognition of outstanding contributions to the understanding of Waldenstrom's macroglobulinemia. The forum was held at the University of Sydney Clinical School at Concord Hospital. Myeloma patients also attended the forum, with Waldenstrom's patients having a separate session stream with Professor Dimopoulos. In the WM stream Professor Dimopoulos spoke on new directions in WM research and therapy. In this session he responded to WM patients' questions following the 'Ask the Doctor' format used at IWMF Ed Forums. The forum was webcast and is still available on YouTube at <http://www.youtube.com/channel/UCTGoXj4ufw7KvulofbCjM4Q>

There was a WM display exhibit before the forum. The materials sent out to Australia by the IWMF office were highly sought after, especially the IWMF booklets and DVDs of the IWMF Ed Forum sessions.

A Bloody Great Night Out! The gala cocktail party was held after the forum with Professor Dimopoulos attending. \$110,000 was raised for blood cancer research. Eighty per

The International Scene, cont. on page 23





The poster for A Bloody Great Night Out! – the gala cocktail party at the conclusion of the educational forum where \$110,000 was raised to support blood cancer research in Australia and Greece.

cent of funds raised will go towards the leading blood cancer research at Concord Cancer Centre, Concord Hospital, and 20% towards Professor Dimopoulos' world-leading research in Athens.

"More than 350 guests attended. It was a wonderful night with a tremendous vibe and community spirit in the room," said **WMozzies'** **Mary Nassibian**, co-chair of the community fundraising committee. "The \$110,000 raised means that dozens of additional patients with blood cancer will be able to participate in world-leading clinical trials and have access to more than \$1 million worth

of new medicines. It offers greater hope for a cure and a better quality of life."



At the A Bloody Great Night Out! gala, from left to right: Catherine Virgona, Professor Meletios Dimopoulos, Mary Nassibian, and Rachel Brook.

Associate Professor Judith Trotman, Director, Clinical Research Unit, Concord Haematology, Concord Cancer Centre, said, "We currently collaborate with Professor Dimopoulos in relation to patient care. However, as with our other strong European partnerships, as a result of these funds raised, we will now be able to expand this collaboration in the area of research. This will ensure even greater success in finding cures for blood cancer patients in both Australia and Greece."

WMozzies are participating in patient advocacy initiatives to the Australian government by the Leukaemia Foundation. WMozzies have submitted individual impact statements to parliamentarians at Parliament House Canberra on 21

November. The main concern was that the new FDA WM treatments are not yet available under the government funded pharmaceutical benefits scheme (PBS). Rituximab, fludarabine, and chlorambucil are funded by the PBS, but the new treatments such as bendamustine and ibrutinib are not.

Two telephone forums for WMozzies in all States have been held this year hosted by the Leukaemia Foundation. In addition there have been WM patient support meetings held at the Leukaemia Foundation in Brisbane and Sydney.

Andrew Warden, WMozzies, reporting

NEWS FROM EUROPE

A WEBSITE PAGE FOR EACH EUROPEAN COUNTRY IN ITS OWN LANGUAGE

For each country in Europe a new website page is now available at www.waldenstrom.info. These pages can also be reached via the www.ewmnetwork.eu site. At the top right and bottom right corners of each page you will find pop-up menus listing the countries: just click on the flag or name of the country you are interested in and you will be taken directly to the page containing the WM related information relevant to that country. The aim is that eventually each country will have a named contact person to take care of the country's page. Once that contact person has been identified, she or he will be able to keep in touch with anybody who sends an e-mail or provides a telephone number. The contact person will also receive a login code from the webmaster of www.waldenstrom.info, to enable simple messages or information (such as for a possible WM patient contact meeting in their country) to be posted on the country's page. Think of country pages as notice boards to enable information to be shared and contacts to be made within each country, leading, we hope, to the setting up of patient support and advocacy groups across Europe.

EUROPEAN CONSORTIUM FOR WALDENSTROM MACROGLOBULINEMIA (ECWM)

The ECWM (www.ecwm.eu) has the vision of combining the expertise of clinicians, pathologists, and researchers across Europe to develop novel strategies to diagnose, assess, and treat patients with WM. The ECWM is based around an international group of experienced clinicians connecting all major national clinical study groups. This "clinical intergroup" forms a unique platform for setting up the large and ground-breaking clinical trials that are otherwise so hard to organize for a rare disease such as WM. Currently several clinical trials are in progress which offer WM patients novel therapeutic approaches under closely controlled conditions.

On Saturday August 16, the Medical Advisory Board of the European WM network will meet with their EU country affiliates in London during the IWWM8 workshop to be held August 14-16.

Marlies Oom, Secretary EWMnetwork, reporting





The large group overflowed the room when the Waldenström France Association convened on September 28 to hear a presentation by Dr. Véronique Leblond.

WMUK

WMUK has been busy, with important projects coming on stream. A priority was a new website at www.wmuk.org.uk to cope with the increased demand for WM information on mobile devices as well as delivering video and an increased range of *Patient Tales*. Other innovations include a secure doctor area for the new WM Doctor Forum (WMUK being a partnership of patients, carers, and doctors), and an upgraded UK online patient forum replacing the one created by our late moderator, Raphael Altman.

An enthusiastic team of volunteers has developed the first UK patient online questionnaire, which should provide much needed information about UK treatment patterns. There is also a projected clinical questionnaire from the WM Doctor Forum to other doctors and centres, modeled on a successful Dutch project. It is also likely that WMUK will support the creation of a UK clinical data registry: secure anonymous data entered by doctors with patient permission which will enable outcomes of treatment to be monitored and more candidates for medical trials to be found.

A first meeting of the WM Doctor Forum will take place in August in conjunction with the upcoming IWWM8 scientific workshop, August 14-16.

The UK has had two WM groups, a support group run by Nigel Pardoe and Cheryl Luckie and WMUK. After ten years of hard work, Nigel and Cheryl have decided to step back and travel the world. Support group management has been handed over to WMUK so that there is now a single point of UK contact.

We are lucky to have an excellent ongoing close working relationship with the IWWMF, which allows us to share information and ideas to the benefit of patients on both sides of the pond.

Roger Brown, WMUK, reporting

WALDENSTRÖM FRANCE ANNUAL MEETING: SEPTEMBER 2013

The annual meeting of the Waldenström France Association

was held on September 28 in Paris at Broussais Hospital on the premises of *Alliance Maladies Rares*. Regrettably, our President, Michel Houche, had undergone an autologous stem cell transplant the previous month and was not yet authorized to travel; quite understandably, his wife Brigitte, the secretary of the association, did not want to leave him alone. Our small team of volunteers therefore had to manage the task at hand in the absence of these two experienced organizers. As it happened, the number of attendees was large but the rooms put at our disposal were small. A truly challenging start to the day! The volunteers, however, rose to the challenge, offering a very warm reception to all the participants, more than half of whom were attending for the first time. After the buffet for 50 people, another ten newcomers from the Paris area turned up, thus completing the audience shortly before the arrival of Dr. Véronique Leblond.

Dr. Leblond began her lecture by explaining that she had been interested in the disease WM thanks to the IWWMF. As she recounted, in 2000 she was invited, together with a small group of other hematologists, by a newly formed association of patients affected by this disease, the IWWMF in other words, to attend a meeting in Bethesda, Maryland. At this meeting the doctors decided to work together and to meet two years later. Since then the IWWM – the International Workshop for Waldenström's Macroglobulinemia organized by Dr. Steven Treon – has met on alternate years for a workshop of WM specialists. In 2012 more than 200 clinicians and researchers gathered for IWWM7 in Newport,



Dr. Véronique Leblond at the meeting of the Waldenström France Association on September 28.



Rhode Island, USA. In August 2014 IWWM8 will take place in London.

Dr. Leblond outlined the disease known as Waldenström's macroglobulinemia, covering diagnosis and its outcome, the decision to treat or not to treat, as well as the treatments available at present. She spoke emphatically to the fact that there is nothing like a standard treatment, so that every patient is treated according to his or her history and personal circumstances, with a view to possible future treatments as well. From the outset Dr. Leblond invited the attendees to interrupt her briefly if they had any questions on a point that she had just covered. Many took advantage of her invitation, resulting in a very lively session. Dr. Leblond detailed the broad range of drugs available to date and explained that specialists are turning more and more to targeted treatments. The discovery of the genetic mutation MYD88 L265P present in 90 % of WM patients has opened the way to specific, targeted therapy. Also, the fact that ibrutinib has been granted breakthrough therapy designation for WM opens very encouraging possibilities.

Dr. Leblond then insisted on the importance of clinical trials. While drug development moves very fast, the dreaded toxicity of new drugs sometimes appears only after an interval. It is therefore necessary to carry out random trials involving a number of patients large enough to warrant valid statistical results. As WM is a rare disease, the experts decided to group together at the national level as well as at the European level.

Dr. Leblond is the chairman of a group of co-workers from 90 clinical centers conducting research on CCL and WM: the FCGCCL/MW (*Groupe coopératif Français pour la CLL et la MW*, or French Cooperative Group on CLL and MW). Recently, the European Consortium for Waldenström Macroglobulinemia (ECWM www.ecwm.eu) joined forces to combine the expertise of clinicians, pathologists, and researchers across Europe in developing novel strategies to diagnose and treat WM patients. Dr. Leblond announced two upcoming clinical trials for WM patients in 2014. A randomized clinical trial starts January 2014 for RCD (Rituxan, cyclophosphamide, dexamethasone, also known as DCR) with or without bortezomib. This trial will enroll 370 previously untreated patients. To test ibrutinib, a European randomized trial for relapsed and refractory patients is planned for later in 2014. Ten of the twelve French trial centers will participate. In this trial ibrutinib will be compared against rituximab delivered subcutaneously on an extended schedule.

After this very encouraging news, Dr. Leblond answered questions from the participants for the next hour. During the break for refreshments patients were able to further ask her for personal advice. We were really fortunate to welcome such a competent and receptive specialist! During the dinner that evening we all signed a card to our President Michel telling him that we had missed him and Brigitte and that "We're counting on you for next year!"



Patrice (second from right) and teammates at the Toulouse marathon.

WALDENSTRÖM PATIENT RUNS THE TOULOUSE MARATHON IN FRANCE: IS NEW YORK NEXT?

Patrice (second from right) is a French Waldenström patient who went through two chemotherapies, R-CHOP in 2005 and FCR in 2009, and also suffered serious pneumococcal meningitis which almost had the best of him. Nevertheless, he was able to run the Toulouse marathon in France as a team member on Sunday, October 23. His team performed extremely well, coming in 386 out of 537 teams. Patrice, a strong advocate of sports as a part of a healthy way of life for cancer patients, received his teammates' warm congratulations on his achievement. What is next for Patrice? Perhaps the legendary New York marathon...

Nicole Bastin, Waldenström France Association, reporting

BELGIUM (FLANDERS) SYMPOSIUM: ANTWERP OCTOBER 2013

The Contactgroep Myeloom en Waldenström Patienten Vlandereen (CMP) started in 2003 for multiple myeloma patients. In 2008 the board decided to start a subsection for WM patients and has since adapted the statutes so that it is now the patient organization for multiple myeloma and Waldenström patients. Currently CMP counts 96 WM and 454 MM members. Perhaps this success is a result of the high priority CMP gives to the three pillars of its organization: provide information, offer support and contact with fellow patients, and engage in advocacy to strive for better access to the best treatment.

2013 was a festive year and was celebrated by two symposia, one for MM and one for WM patients. On October 19, nearly 50 interested people came to Antwerp to attend the WM symposium. They followed attentively the lectures of the prominent physicians who were invited. Dr. Jan Lemmens, head of the Department of Haematology of Sint-Augustinus, Antwerp, chaired the morning session. The disease itself, symptoms and complications, diagnosis and treatment,

The International Scene, cont. on page 26



were the topic. Dr. An Vandebroek, medical oncologist at Middelheim Hospital in Antwerp, gave a presentation on nutrition and exercise in cancer. Dr. Alexandra De Vooght, haematologist at Middelheim Hospital, discussed some case studies. However, the icing on the cake was the presentation of a patient booklet that, with limited resources but with perseverance and dedication, has finally been completed. During the coffee breaks, the lunch, and particularly during the reception afterwards, there was opportunity for informal contact with fellow patients.

Worth noting are the concluding words of the doctor whose presentation filled the whole morning: *Waldenstrom's is a rare disease with a chronic course and reasonable prognosis. The symptoms can be very diverse, but some symptoms are persistent and difficult to treat. The hope is for prompt refund of available medications, as well as for the new medications such as new immunomodulators and monoclonal antibodies. Participation in clinical trials is a way to get early accessibility to this medication and improve our knowledge about this disease.*

This sounds like a cry for help from the medical world. It is also a rallying point of our policy: ability to participate in clinical trials, some transparency in the access to and reimbursement of orphan drugs. The fight is not over. There is still a lot to do.

We have high expectations for the upcoming symposium on January 30, 2014. It will take place in Ghent at the invitation of the Belgian Hematological Society (BHS) which will be holding their yearly meeting. On the agenda we placed a discussion on accessibility and reimbursement

of orphan drugs! More on this in the next *Torch*.
Joanna Van Reyn, CMP Flanders, reporting

FINNISH SUPPORT GROUP

In Finland, the WM support group activity started in 2006, and normally we have one meeting annually. This year we had two. In the spring we participated in an overnight sea cruise from Helsinki to Tallinn, the capital of Estonia. This was organized with several other rare cancer groups by the Association of Cancer Patients in Finland. Each of these groups also holds separate meetings.

The second meeting took place October 26 in the Hotel Scandic in Tampere, which lies 150 km north of Helsinki. Again almost thirty patients and caregivers came from various parts of Finland. The Association takes care of all practical issues for these meetings: invitations, booking the facilities, arranging the doctor speaker. Everything is free of charge for participants, including a tasty lunch, coffee, and snacks.

The first speaker was Mrs. Leena Rosenberg-Ryhänen from the Association. Her theme was the quality of life and cancer. Our visiting doctor was Dr. Tero Pirttinen from Tampere City Hospital. After an informative report on WM, there was time for several questions. Last but not least, we held the traditional "round table" part of the meeting. Each participant told "my story" – the history of his or her WM treatments, possible symptoms, and side effects.

Next year we shall meet again, somewhere in southern Finland.
Veikko Hoikkala, WM Support Group Finland, reporting

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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

COLORADO & WYOMING

On a beautiful fall day in the Rockies, thirteen group members gathered in a conference room at Presbyterian-St. Luke's Hospital in midtown Denver. The plan was to watch the Garden and Weeds DVD by Dr. Morie Gertz of the Mayo Clinic. However, most had already seen this invaluable WM overview. Instead, the format became a sharing discussion fueled by a bountiful table of breakfast potluck goodies. Popular topics included bendamustine side effects, Rituxan issues and how to manage them, insurance coverage of certain drugs and procedures, the availability of ibrutinib in Denver, and details of stem cell harvests by three attendees. A winter meeting is planned for January or February. In April, the Rocky Mountain Blood Cancer Conference will take place in

Denver. Dana-Farber's Dr. Irene Ghobrial will be the keynote speaker. The LLS (Leukemia & Lymphoma Society) hopes to have a WM breakout room where Dr. Ghobrial will lead a discussion of WM specific topics.

GEORGIA

In November, a big group turned up to hear **Judy Roseman's** personal story of her participation and experiences to date in Dana-Farber's ibrutinib clinical trial. Judy began the trial in March 2013 and has had excellent results with no side effects. A local angle made the story even more appealing: the potential availability of clinical trials of ibrutinib at the Emory Winship Institute. The other significant topic that engendered much conversation was an update on the *Imagine a Cure* Campaign. Support group leader **Mal Roseman** encouraged the group to attend the May IWMP Ed Forum in

Support Group News, cont. on page 27





Members of the Chicago area support group assembled for their annual picnic on a perfect day in August.

Tampa since it is close enough to Atlanta to enable members to drive.

ILLINOIS

Chicago Area/SE Wisconsin

The Chicago area support group had its fifth annual picnic at **Mike and Sara Thran's** home on Saturday August 24, 2013. The weather was perfect in the suburban west side of Chicago. This was the third year that the Thrans have hosted the picnic. Sara graciously served burgers while support group leader, **Don Brown**, made his special "beer-simmered" brats. This year there were two versions to choose from: Wisconsin dark beer or Boston lager. In addition, at the fall meeting in October, the group reviewed the Ask the Doctor DVD from the IWMF San Diego Educational Forum. The first meeting of 2014 will take place in April, and plans include a guest speaker.

INDIANA

In September, practicing lawyer Jennifer Terry spoke on a hot and timely subject: the Affordable Care Act. The large group met at the LLS offices in Indianapolis where Ms. Terry led a vigorous discussion on the Act and other insurance matters. The LLS provided breakfast snacks and coffee as well as miniature candy bars. The Indiana group meets about three times a year. To avoid traveling in potentially bad winter weather, the next meeting is planned for early spring. The agenda will center on DVDs from previous IWMF Educational Forums.

NEW YORK

New York City

The turnout for the November meeting was uncharacteristically low for this tuned-in group. However, one newly diagnosed patient attended. She arrived feeling confused and worried and benefited from the intimate group size and informal format. She left feeling a bit calmer and more hopeful, a very good outcome that re-energized all the attendees

Eastern NY/Western New England

Holiday celebrations got off to a very good start in early December with a party at the home of **Sandy and Kent**

Solomon, who graciously welcomed the group members and their families for the second year of this now annual event. As the group's focus has always been great food and good friendship, this party was no exception. The potluck 'endless buffet' featured many delicious creations from our plethora of super-gifted cooks. Between bites, members engaged in spirited conversations about families and travel plans. And there were many happy toasts for good cheer and great health throughout 2014! The group alternates parties with meetings on more WM-specific topics. The meeting on January 11 will feature Deacon Frank Thomas, M.D. Dr. Thomas is a retired oncologist-hematologist. He will focus on the role faith and religion might play when people face a serious medical condition. Expectations are for a stimulating presentation and an interesting discussion. This meeting was originally planned for November but has been rescheduled for the January date. The group continues to be grateful to hold meetings at the American Cancer Society's Hope Club in Latham, NY. Up next after the January meeting: the annual restaurant "break the winter doldrums" outing in March.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

On August 25, a perfect sunny day in Pittsburgh, members gathered outside for a patio meeting at the home of Board Trustee **Marcia Klepac** and her husband **Glenn**. A mix of WMers, some in the midst of treatment, some enjoying the coveted 'treatment-free' period, and another member on watch and wait shared their experiences and hopes regarding new treatments on the horizon. Group leader Marcia Klepac, who attended the IWMF Ed Forum in May 2013, reviewed highlights from presentations given by Drs. Treon, Ghobrial, Maloney, Hardy, and the annual Ask the Doctor session. The topic of integrative medicine stimulated an enthusiastic discussion about exercise habits. It seems this active group of WMers participates in running, swimming, and yoga. The afternoon ended with a delicious potluck dinner that included an abundance of outstanding desserts. No one complained. On October 6, about thirty members met at an alternate location, the library in Bedford, Ohio, (near Cleveland) for a webinar

Support Group News, cont. on page 28



with the Philadelphia support group. The speaker, Christine Spiroch, Ph.D., PA-C, from the Center for Integrative Medicine at the Cleveland Clinic, gave a very informative presentation, "The Integrative Medicine Approach to Living with WM." Topics, such as nutrition, supplements, lifestyle, social support, and mind-body approaches stimulated much interest and questions from both groups. A fun and easy energy-work type of activity got us all up and moving. Special thanks to the technical team of **Pete DeNardis, Ron Yee, and Don Brown** for their expertise in providing the opportunity to connect with another group via the Internet. The sharing portion of the meeting touched all in the group as a newly diagnosed member expressed her personal feelings about diagnosis and implications for her quality of life. Many shared their reflections of their own diagnoses and offered support and information to the new member. Both before and after the program, members enjoyed socialization and a great selection of potluck dishes.

OREGON/SOUTHWEST WASHINGTON

Integrative therapies were also on the agenda for the quarterly meeting in October with a presentation "Integrative Therapies and the Cancer Experience" by Mary Thies, an oncology nurse and massage therapist. In addition to Swedish massage, Mary also does Reiki energy therapy and touch therapy. Reiki is a Japanese healing practice that uses hand positions over the body to promote healing and relaxation. Ms. Thies gave an overview of how different types of bodywork and energy work can compliment Western medicine and covered the benefits of such approaches for oncology patients. She reviewed safety precautions for oncology massage and demonstrated reflexology and acupressure. The turnout was sparser than usual with a dozen in attendance, but a spirited discussion ensued. The support group is a partnership with the IWMF and the local LLS chapter, which provides meeting locations, lunch, and helps with publicity. Ten members of the support group participated in the local LLS "Light the Night" walk and fundraiser on October 19 to honor the group's founder and longtime leader, **Joan Berglund**, who has been undergoing chemotherapy. Walkers crossed a bridge in downtown Portland and were treated to a spectacular fireworks display. The next meetings are planned for January 25 and April 26, from noon until 2 pm at the Fairfield Inn and Suites, 6100 SW Meadows Road, Lake Oswego, OR (near the junction of I-5 and Rte. 217).

PENNSYLVANIA

Harrisburg Area

The November meeting of the Southeastern PA IWMF support group met at Messiah Village for lively discussions of current treatments, recent life "ups, downs, and curves," and general camaraderie. The gathering of nine patients and caregivers was a bit smaller than normal due to illness, vacation, and a

little one's baptism. Optimism is one of the best medicines, it was agreed, and sharing it with one another is a great pleasure. A continuing concern for members is finding local physicians who will listen to patients and the Waldenstrom's experts. When information about the benefits of dandelion root tea was being discussed, one member wondered if dandelion wine would also be good. Yes, laughter is a cure to be sure. The meeting schedule has changed to three times a year, on the second Sunday of April, August, and November 2014. But telephone calls for support can happen any time.

Philadelphia

The Philadelphia group participated with the Western Pennsylvania/Eastern Ohio group in the October webinar with Dr. Christine Spiroch of the Integrative Medicine Center at the Cleveland Clinic. An integrative approach to living with WM is a topic that frequently comes up at meetings. Everyone is looking for a way to keep his or her WM at bay. Dr. Spiroch passed along many good tips. The discussion of an anti-inflammatory diet sparked a great deal of interest. Webinars work quite well for support groups sharing speakers, and plans are afoot to continue the effort. In November the group watched the Ask the Doctor DVD from the 2013 Ed Forum, passed the popcorn, and discussed various topics that were brought up. This is always a stimulating meeting since such a variety of topics are covered in the Ask the Doctor sessions.

WASHINGTON

The Fred Hutchinson Cancer Research Center, Seattle Cancer Care Alliance (SCCA), presented a symposium in October dedicated to Waldenstrom's. The featured speakers were Dr. Edward M. Libby, hematologist-oncologist at Seattle Cancer Care Alliance, associate professor at the University of Washington School of Medicine, and associate member at Fred Hutchinson Cancer Research Center; and Dr. Robert D. McCroskey, who works in private practice specializing in hematology and medical oncology with Rainier Hematology-Oncology in Puyallup, WA. Dr. McCroskey opened with a concise history of WM, and Dr. Libby presented the latest treatments, clinical trials, and drugs available today. Using an excellent slide presentation, they spoke to 55 attendees from the Seattle area and a few from Oregon. Attendees were treated to a lavish breakfast buffet before the meeting, and another feast following the presentations, provided (gratis) by SCCA. WMers had sent in questions before the meeting, and both doctors answered all the questions sent, plus more from the floor. Although there was no charge for the symposium, Dr. Libby urged WMers to contribute generously for ongoing research in WM and said he would like to hold a symposium like this every year. The group expressed their great gratitude for these knowledgeable doctors who took personal time to provide the latest information on WM and for the generosity of SCCA for the food and accommodations.



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
jLsLs@aol.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

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

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

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

DELAWARE

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

FLORIDA

Gainesville Area
Harriett Pawliger
352-331-7340
352-219-5674 cell
harrpaw@aol.com

Susan Boulet
352-384-1100
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

GEORGIA

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

HAWAII

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

IDAHO

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

Western

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

ILLINOIS

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

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

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

MINNESOTA

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

MISSISSIPPI

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

MISSOURI

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

MONTANA

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

Regional Contact:

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

NEVADA

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

Regional Contact:

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

NEW ENGLAND

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

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



IWMF SUPPORT GROUP CHAPTER LISTING

OKLAHOMA

Western

Regional Contact:

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

OREGON/SW

WASHINGTON

Joan Berglund
503-668-5037
jbjoanberglund@gmail.com

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

PENNSYLVANIA

Philadelphia

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

Harrisburg, Central and Southeast PA and Northern MD

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

W. PENN, E. OH, WV

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

W. PENN, E. OH, WV (cont.)

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

TEXAS (cont.)

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

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

WASHINGTON

Northwest (Seattle Area)

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

WASHINGTON (cont.)

Southwest (Portland Area)

Joan Berglund
503-668-5037
jbjoanberglund@gmail.com

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

Colin Perrott
colin@wmozzies.com
www.wmozzies.com

BELGIUM

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

CANADA

Alberta

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

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

Montreal

Regional Contact:

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

Nova Scotia

Susan Gagnon
902-446-9533
suearg3x3@hotmail.com

Ottawa

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

CANADA (cont.)

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

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

GERMANY

Regional Contact:

Dr. Rolf Pelzing
rolf.pelzing@t-online.de

GERMANY (cont.)

Morbus Waldenstrom (MOWA)

Anita Waldmann
+49 (0)61 423 2123
info@myeloma-euronet.org

GREECE

Alexia Kapralou
+30 210 6858574
kapralou_alexia@hotmail.com

INDIA

Regional Contact:

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

Mumbai & Western India

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

IRELAND

Sheila Thomson
sheilathomsonmail@gmail.com
+35312822481

ISRAEL

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

JAPAN

Regional Contact:

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

THE NETHERLANDS

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

Nigel Pardoe & Cheryl Luckie
+44 0208 3263286
info@wmsupportgroup.org.uk
wmsupportgroup.org.uk

WMUK

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

Birmingham & West Midlands

Geoffrey Willsher
+44 0121429 1038



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 (Cytoxan)

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

FLUDARABINE with Rituxan

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

IVIg

Ron Linford 865-675-9895
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

SPLENECTOMY

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

STEM CELL TRANSPLANTS

AUTOLOGOUS

Doug Bentley 805-937-3619
cpbentley@hotmail.com

AUTOLOGOUS (cont.)

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

VELCADE

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

NEWLY DIAGNOSED

Guy Sherwood 765-282-4377
guysherwood@comcast.net
 Sallie Moore 516-795-3746
Smooore6042@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@sccoast.net
 Renee Paley-Bain 203-744-7851
paleybain@aol.com
 Joel Rosenblit 503-365-7074
rosenblitj@msn.com

YOUNG WM

Ryan Scofield 312-576-9429
ryanscofield@gmail.com



THE LIFELINE

YOUNG WM (cont.)

Bob Baile 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@yahoogroups.com
colin@wmozzies.com

BELGIUM

Joanna Van Reyn +32 9 335 46 60
joanna.vanreyn@cnp-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
 Michel Houche
houchemichel@wanadoo.fr

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)

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
veraleon@comcast.net

SPANISH LANGUAGE TALK LIST

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

SWEDEN/NORWAY

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

NORDIC COUNTRIES TALK LIST

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

UNITED KINGDOM LIFELINE

2Cda (CLADRIBINE)

Roger Brown +44 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.manning555@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

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

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

Jeff Atlin (Toronto, ON) 905-707-5640
jeffatlin@hotmail.com
 Rod Anderson (Cobourg, ON) 905-372-2410
rod@rodmer.com



**SINCE AUGUST 2013, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

Raphael Altman

Sue Herms

John Austin

James & Susan Cox
Patricia Fox
John & Pat Gallagher
Robert & Mary Honegger
Carl Larson
Guy & Joan Lithwin
David & Donna Orner
Roger & Barbara Robinette

Edward Baer

Cindy Baer

Freddy Bastin

Nicole Bastin

Philip Bellows

Kathy Bellows

Beverly Boardman

Ken & Nadine Dale

Miriam Brensinger

Bob & Eileen Whitman

Dr. Blythe K. Brown

Marina Skulsky

Joe Cannata

Barbara Howell

Nick Carrick

Arlene Hinchcliffe

David Louis Conger

Dennis & Celeste Bond

Joe Coppi

John & Genevieve Lucas

Harold Crites

Margaret Crites-Whaley

Mary deBruyn

Alden & Doris Halloran

Pat Dellinger

Larry & Patti Leiningner

Mike Dewhirst

Sue Herms

Ron Draftz

Jean Arndt
David & Penny Kirby
Carol & Bill Kowaleski
Donna Olson

Ann Jackson Dyson

Cindy Baer

Carolyn Ferrigni

Alice Rooke

Fred Fischer

The Addison Rotary Club
Fred Fischer's Book Club:
Dr. Alan Brodsky
Jerry Kasten
Stuart Morse
Donald & Judith Steine
Leonard Stern
Dr. Paul Tobolowsky

Wayne Fitz

Leza Cole
The Detchon Family
David & Diana Heckman
Robin & Angela Lovelace
Stephen & Maeve Rish
Thomas & Jeanne Stancel
Bradley & Diane Tomlinson
Vince & Sara Wakefield

Jerry Fleming

Vince & Susan Santa Maria

Paul Fortier

Jan Jones
Barrie Leach
Murray Shaw

Arnold Goldberg

Muriel Goldberg

Walter Grassler

John & Martha Brexl
Dick & Judy Lainson

Tom L. Hanson

Virginia Hanson

Celeste Healy

Chris & Denise Freidhof
Mary Harter
Michael Harter & Sandra Cermele
Jackson
Tom Marciani

David Hibbs

The Trust Company

Florence Huskins

Jeff Prupis & Wanda Huskins

Edith Jevotovsky

Marjory Silverberg

Terry Kilsby

Kevin Kilsby

Fred Kite

Ronald & Judith Olan

Dorothy Kuveke

Paul Kuveke, Jr.

Barbara Laine

Al & Rita Wenkert

Theodore Latala

Stephen & Kathleen Buhe
Marianne Schnabel

Mike Lesmister

Gay Lesmister

Marilyn Ruth Litton

Jan & Marvin Michael

James McLean

Rilla McLean

Chuck Michel

Laurel & Emily Michel

Leo Morin

Gary & Sharon Dionne
Audrey Thompson
Brad & Linda Thompson

David W. Morrow

Charles & Joan Carlson

Robert Murenbeeld

Aaron Murenbeeld
Walter & Antonia Murenbeeld

Anatoly Novik

PEI Genesis, Inc.

Lillian Coslow Pollak

Linda Nelson

Sharon Potesman

Ira & Sue Bernstein

Robert Pye

Christopher & Elizabeth Pye

Rodney Reindl

Sharon Reindl

Carol Rodgers

Melissa Rodgers

Michael Roiger

Jim & Louise Thompson

Jackie Romanello

Tom Romanello

Estelle Roodman

Stanford Roodman

Susan Rubenstein

George & Abby Alexiades
Nancy Allen
American Gaming Systems
William Anspach & Terezia Rabai
Steve & Erica Attanasio
Tony & Sandy Attanasio
Babs Balson
Harold & Roberta Barron
Herb Beller
Joan Berger
Robert Berger
Ira & Sue Bernstein



**SINCE AUGUST 2013, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

Susan Rubenstein (cont.)

Jonathan Bilzin
Jay Blecker
Richard & Debra Brady
Albert & Jean Broday
Gwen Callans & Biff Ruttenberg
Marge & Lew Collens
Allen Debevoise & the Machinima Team
Harold Dembo
Derek & Marla Dobrin
Christie Dunne
EQS Enterprise
Bette Feinerman
Mike & Ercelle Feldman
Jennifer Fichera
Marty & Donna Field
Donald Finkelman
Susan Finkelman
Caryn Gallop
William Garmisa
Emily Gasner
Eleanor Glazer
Robert & Linda Glick
Eden Godsoe
Greg & Marlene Gosser
Austin Hirsch & Beth Gomberg-Hirsch
Barbara Hubbard
Jim & Kathy Hurley
Illinois Coin Machine Operators Association
Jerry & Ann Jaeger
Joel Jastromb
Ann Skinner-Jones
Leslie Nathanson Juris
Laurie & Bruce Kaden
Thomas Kane
James Klutznick
Ross & Heidi Laloggia
Warren Lavey & Dr. Holly Rosencranz
Phil & Andi LeBoy
Karen Leeds
Paul & Janet Leeds
Kyle Lennox
Kevin Linker
Judy Markey
David Missner
Ted Jadwin & Ellen Morris
Mickey & Susie Neuwelt
Howard & Sheila Pizer
Neil & Patti Posner
Beth Powers
Robert Rashkin
Jordan Reiss
Larry & Corinne Richman
The Rivera Family
Collin Roche
Bob & Nancy Rosenblum

Susan Rubenstein (cont.)

Don & Sandy Rothbaum & Family
Martha Rothbaum
Jeffrey Rubenstein
Todd Ruddick
David & Ginger Russ
Keith Russo
David & Jon Ruttenberg
Donald Schaumberger
Leonard & Joyce Schrager
Alan Schwartz
Mr. & Mrs. Michael Sear
Gordon & Carole Segal
Ronald & Judith Sharlach
Charlie Sheffer
Nancy Shields
David & Diane Sigman
Marc & Marcy Simon
June Sochen
Lisa Spinali
St Andrews Foundation
Avy & Marcie Stein
Josh & Jenny Stein
Jerry & Susan Steinberger
Stan & Nancy Steinik
David & Jory Strosberg
Carl & Verna Tiarks
Robert Toomey & Steve Meyers
Allan & Romlee Weinstein
Richard & Bobbi Wexler
Tom Wirtshafter & Carol Marks
David & Marilyn Wittenberg
Richard & Nadine Woldenberg
Jeff & Lauren Wurtzel
Paula Klein-Zeid

John Sanderson

Santosh Anishetty
Clay Conway
Dan & Peg Cook
Ron & Janice Dawson
Julian Dench
Clark & Judy Foster
Marvin & Lucinda Fudalla
Mr. & Mrs. Yousif Ghafari
Tom & Beth Greenwood & Family
Mark & Claire Haley
William & Kathleen Haley
Angela Freeman Kurolvech
Loren & Patti Plisco
Jack & Cheryl Songster
Andreas Stahr
Bert Wolfram

Leonard Schectman

Merle Weston

David Alexander Schick

Lorraine Schick

Jerry Seeman

Carolyn Olson

Judy Shaffner

Nancy Nevitt

Dan & Estella and Ian Singer

Raymond Valadez & Rose Crownover

Bernardine Smokler

Arthur & Linda Solomon

Wallace Spring

Stephan & Sonia Boehringer
Jack Dorak
Mary Dorak

Charles Vassallo

Lucrezia Vassallo

Harry Vaughan

Linda Vaughan

John Wasniewski, Jr.

Jeffrey Bright
John Carlson
Delaware Department of Justice,
Consumer Protection Unit
Delaware State Osteopathic Medical Society
John & Peggy Gerber
Maureen Kelly
Gary & Judy Kemeny
Robert & Cheryl Kroyer
Kenneth & Mary Louise Kubacki
Bill & Mildred Mentzer
James Murphy
Barbara Rhoades
Thomas & Jeanne Rueger
John Sheehan
Robert & Lorraine Terruso

Joseph Weintraub

Noah & Phyllis Fields

Julia Wesmiller

Harold Wesmiller

Kenneth Wilson

Charles & Joan Carlson

Nicholas Wyman

Rebecca Ketchum
Joseph Wyman

Albert Zucker

Jeffrey & Julie Kuhn & Family

Harold Zfaney

June Zfaney



**SINCE AUGUST 2013, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:**

Dr. Rafat Abonour

Angelique Draftz

All WM Survivors

Anita Lawson

Jeff Atlin

IMBAO

Gail Arcari

Cheryl Slover-Linett

Peg Bohanon

Elaine Bohanon
Michael & Lise Bohanon

Mr. & Mrs. M. Bower

Ernie & Angela Bower

Don Brown

Carl & Elly Harrington
Sue Herms

Gary Calamari

Michael Landers
Neil Pifer

Mary Ann Chartrand

Arlene Davis

Sharon Cook

Stewart & Sarah Gotlieb

Rose Crownover

Daniella Crownover

Denise Czitterberg

Dave & Barb Grover

Amy & Dennis Daraghy

Daniel Odell

Joyce Deaton

Lois Kleinhenn Lanier

Peter DeGreen, III

Catherine Oliphant

Peter DeNardis

Edward Goldberg & Linda Trytek
Andrew Warden

Joy Dulin

Michael & Jan Dulin

David Eggleton

Jeffrey & Megan Stepputtis

Marie Faust

Judith Austin

Cynthia Gavin

Joyce Sullivan

Dr. Daren Grosman

Joel Pollack

Ali Handal

Michael & Jennifer Poole

Carl Harrington

Jack Burns

Charles Heatley

Marjory Heatley

Marci Heller

Laura Simmons

Wayne Hodge

Lamoine Hodge

Edward Isaac

The Kahn-Sharp Family
Ross Miller's Mitzvah Project
Steven & Adrienne Novick
Margo Smiley

Leif Jacobsen

The Family of Leif Jacobsen

Joe Janda

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

Jonathon Klinck

Cynthia Ruhl

Moshe Kwart

Velma Kwart

Gail La Bruno

Carl & Elly Harrington

Janet Livingston

Charles Caroselli

Ruth Lizotte

Barbara O'Neil

Dan Marder

Dennis & Felice Killian-Benigno

Judith May

Susanna Bensinger

Christopher Moakley

Julie Moakley

Tom Myers

Carl & Elly Harrington
Sue Herms
Elizabeth Holcomb
Vasilis & Alice Riginos
Bob & Rebecca Spencer

Marie Navarra

Joy Crabb

Raymond V. Nadolny

Anthony Patanella

Gina Odell & Michael Smith

Daniel Odell

James Ortoleva

Mr. & Mrs. Chris Lamon

James Paxton

Lynda Nielsen

Joel Pollack

Martin, Judith & David Schneyer

Pratt-Hawkes Family

Ethel Pratt

Anna Mae Quitter

Janine Quitter

Alice Riginos

Cynthia Riginos
Gus & Linda Swift

Donna Roszell

Bookworms Book Club

Brian Sachs

Marcia Sachs

Giulia Adamo Savery

Antonell Marotti

Ryan Scofield

Richard & Karen Scofield

Michael J. Smith

Dominique Smith

Paul E. Smith

Chris & Natalie DeLaGuardia
Ralph & Elizabeth Smith

Vincent Staples

Ann Staples

Ron Ternoway

Greg & Diane Dika

Dr. Steven Treon

Robert Carroll
Anita Nelson
Cathy & Arthur Richards

Fred van Hartesveldt

Christina McElwee
Grand Rapids Community College
English Dept.

Ubaldo Vitali

Bruce & Judy Bernbaum

Lisa Weldy

Heather D'Alessandro
Ansley Dauenhauer
Christina De Vine
Gregory & Karen Doren
Kathleen Erb
Sherry Elford
May James
Dawn Jung
Daria Karetnikov
Julie Kates
Doreen Keptner
Rebecca Stern Klausner
Larry & Nancy Kornwise
Monica Lesnau
Kimberly Mecham
Michigan Operations Community
Outreach Team
Deanna Murray
Stephanie Parmele
Keith & Nancy Ryder
Carrie Storer
Thomas Tessy
Nicole Truscott
Julie Turner
Ken Weldy
Heather Witt
Alissa Yoder
Kelly Zalusky

Marcia Wierda

Evelyn Hamberg
Judy Motman
Betty Lou Terhaar
Andy & Tracie Wierda

Ric Williams

Karolinn Green

Chris Wiman

Brent & Christine Harmes

Ronald Yee

Alexis Long





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

Website Translations

One of the goals of the IWMF is to provide information and support to everyone in the IWMF community (patients, caregivers, friends, and medical professionals). One means of achieving this is the IWMF website (www.iwmf.com) which until now was available only in "American English." We are pleased to announce that the IWMF website can now be viewed and read in multiple languages. The automated tool that processes the translating may not be 100% grammatically correct, but the spirit and intent of the information presented remains the same.

You may access the language of your choice by clicking on the **Select Language** drop down tab located in the upper right hand corner of the IWMF website home page.

IWMF Publications available in Spanish Translation

Many of the IWMF's publications are available in French in addition to English. And, as a result of a generous donation from one of our members, we are currently in the process of translating several of our publications into Spanish as well. In fact, we have just completed translating *Treatment Options* into Spanish and it is now posted on the IWMF website: www.iwmf.com/publications/downloads.aspx

To immediately download the publications now or to order printed copies of selected publications, go to: www.iwmf.com/publications