

INSIDE THIS ISSUE

President's Corner 1

Carl Harrington
Elected Fourth
President of IWMF 1

Introducing Cynthia
Ruhl: The New IWMF
Treasurer 2

IWMF Tissue Bank
Study, a Clinical
Trial Update..... 3

13 New Members
Join Ben Rude
Heritage Society 4

Ed Forum 2012..... 5

My Comforter:
Impressions of
a Newbie 9

Seventh International
Workshop on
Waldenström's
Macroglobulinemia... 10

Presenting
Emil Parente..... 11

Psychological and
Social Needs of
the Cancer Patient... 12

Imagine This: From
Rituxan Project
Team to Patient..... 13

Medical News
Roundup 14

Ryan Scofield
Lives Strong..... 16

Cooks' Happy Hour ... 17

Double Accolades
for Peter DeNardis... 18

International Scene.... 19

From IWMF-Talk..... 20

Support Group
News 23

In the Torchlight 35

PRESIDENT'S CORNER

JUDITH MAY REFLECTS ON HER STEWARDSHIP OF THE IWMF



Serving the IWMF as a member of the Board of Trustees has taken fifteen years of my life, with eight of those years as president, and I don't begrudge a minute of it. Nothing has given me a greater sense of purpose and satisfaction than being a part of the IWMF.

There is a lot of debate about our essential human needs – there is Mazlov's hierarchy and Jungian spirituality and many more ideas of what it means to be a fulfilled human being.

It seems to me, and I'm sure many of you will agree, that the greatest of all human needs is to be a part of something larger than the self.

The IWMF has been perhaps the strongest commitment of my life.

There are those who may think that I deserve the credit for raising millions of dollars for research, increasing member services, expanding our international reach, and bringing dozens of brilliant minds into our special group of research scientists. But it was not me. The credit goes to all the IWMF trustees, the Scientific Advisory Committee, and the several hundred volunteers who

President's Corner, cont. on page 30

CARL HARRINGTON ELECTED FOURTH PRESIDENT OF IWMF



*Carl Harrington,
President-Elect of the IWMF.*

The IWMF Board of Trustees is pleased to announce the election of Carl Harrington to the position of President of the International Waldenström's Macroglobulinemia Foundation.

Carl is a Principal and Founding Partner, since 1999, of *The Marketing Works!*, a strategic marketing consulting company focused upon growth initiatives. Current clients include Ansell Healthcare and Fujifilm; previously Carl found creative business-building solutions for clients such as Johnson & Johnson, the Crohn's and Colitis Foundation of America, Bausch & Lomb, and many consumer products outside of the healthcare industry. Before running his own business, Carl was a senior marketing executive in charge of strategic marketing, new products, and problem-solving for K'NEX Toys in Hatfield, Pennsylvania, Mott's and other beverage products for Cadbury Schweppes in Stamford, Connecticut, McCormick Spices in Baltimore, Maryland, and breakfast foods at General

Carl Harrington Elected, cont. on page 30

OFFICERS & TRUSTEES

FOUNDER

Arnold Smokler

PRESIDENT

Judith May

SECRETARY-TREASURER

Cynthia Ruhl

VICE PRESIDENTS

Tom Myers, Jr.

Marty Glassman

Carl Harrington

BOARD OF TRUSTEES

L. Don Brown

Peter DeNardis

Sue Herms

Robert A. Kyle, M.D.

Elena Malunis

Guy Sherwood, M.D.

Ronald Yee

BUSINESS OFFICE

Sara McKinnie, Office Manager

IWMF SCIENTIFIC

ADVISORY COMMITTEE

Robert A. Kyle, M.D., Director

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

Christos Emmanouilides, M.D.

Interbalkan European

Medical Center, 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

James Mason, M.D.

Scripps Clinic

Gwen Nichols, M.D.

Hoffmann-La Roche, Ltd.

Alan Saven, M.D.

Scripps Clinic

Steven Treon, M.D.

Dana-Farber Cancer Institute

Mary Varterasian, M.D.

Donna Weber, M.D.

M.D. Anderson Cancer Center

INTRODUCING CYNTHIA RUHL: THE NEW IWMF TREASURER

The IWMF Board of Trustees is pleased to announce the election of Cynthia Ruhl to the position of Treasurer of the IWMF. After a lengthy search to fill the position of treasurer, we have found an incredibly experienced and skilled individual.

Cynthia has been a partner with the Los Angeles firm of Hull, Ruhl & Moore, CPAs, since 1982 and has work experience as a CPA for a total of 35 years. She holds a B.S. in Business Administration with a major in Accounting from Drake University and a Master of Business Taxation from the University of Southern California.

To the IWMF Cynthia also brings many years of experience with board work, having served for 25 years as treasurer and on the endowment committee of her church. She has also been on the Board of the Junior League of Los Angeles as well as a local community foundation.

Diagnosed with Waldenstrom's macroglobulinemia one year ago, Cynthia's husband Jon is currently doing well. Jon works as a trial attorney for the United States Department of Justice. Filling the role of caregiver, Cynthia has only the highest praise for the IWMF and the valuable assistance received for her newly diagnosed husband.

Cynthia and her husband reside in Los Angeles and have a 14-year old son who just started high school and is active on the debate team. Imagine life with a trial lawyer and teenage debater! Cynthia is a big fan of USC football and is very excited about this year's season!

We will soon be seeing reports from the Treasurer again in the *Torch* and on the website. The Independent Audit of the IWMF Financial Statements for 2011 has recently been completed and information regarding the Audit and Financial Statements will soon be available for review on the IWMF website.

Please note the new address of the IWMF Business Office.



The IWMF *Torch* is a publication of:

International Waldenstrom's Macroglobulinemia Foundation

6144 Clark Center Avenue • Sarasota, FL 34238

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

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

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

PRESIDENT

Judith May

EDITOR

Alice Riginos

ASSOCIATE EDITOR

Sue Herms

SENIOR WRITER

Guy Sherwood

INTERNATIONAL CORRESPONDENT

Annette Aburdene

SUPPORT GROUP NEWS

Penni Wisner

IWMF-TALK CORRESPONDENT

Mitch Orfuss

CULINARY EDITOR

Penni Wisner

PHOTOGRAPHY

Peter DeNardis

Bob Manning

Roy Parker

Jack Whelan

FORMATTING & PRODUCTION

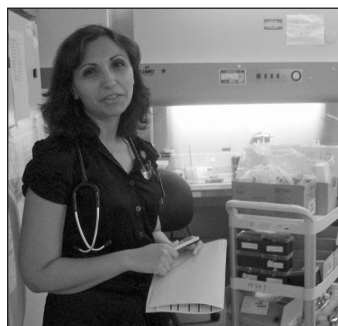
Sara McKinnie

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

IWMF TISSUE BANK STUDY, A CLINICAL TRIAL UPDATE

BY JACK WHELAN, IWMF MEMBER

Making headway against Waldenstrom's macroglobulinemia is challenging. Because our population of WM patients is so small, we receive almost no share of research funds from either government agencies or pharmaceutical



Dr. Irene Ghobrial in her laboratory at the Dana-Farber Cancer Institute.

companies. The priorities of government agencies are set to accommodate majority voters while those of the pharmaceutical companies are influenced by profitability. In either case, research targeting an orphan disease will never be at the top of the list. It is up to us, members of the IWMF, to pool our resources to promote WM research. The amount of money already raised

by this small Foundation in the course of fourteen years is quite remarkable, and the need for such member support will continue. But not all the needed resources are financial. There is another important way that those IWMF members who are WM patients can support WM research: participation in clinical trials.

At the recent IWMF Ed Forum, Dr. Peter Martin of Weill Cornell Medical College spoke on "Choosing a Clinical Trial," and in his remarks Dr. Martin outlined the difference between trials that are observational and those that are interventional (see *Ed Forum Review 2012* page 9 for the full discussion by Dr. Martin). Interventional trials are perhaps more familiar to us, the trials where 'the protocol' (that is, the study plan) defines who can participate, medications, dosage and the study's length of time during which you must adhere to some schedule of therapy such as recurring infusions or a pill-form drug.

Observational clinical trials, by contrast, are studies based on data collected from patients with a particular disease (WM as an example). Such studies can yield a great deal of information about that disease but only when the data is abundant. By sharing our data we also pool our resources in the support of WM research. And there is one specific observational trial underway at the Dana-Farber Cancer Institute that will directly benefit WM patients. I am referring to the Tissue Bank Study, funded by IWMF, by your money. The Principal Investigator is Dr. Irene Ghobrial.

Before I tell you just how easy it is to participate in Dr. Irene's Tissue Bank Study, let me add a word about similar projects in the realm of cancer research. Our friends at the Multiple Myeloma Research Consortium funded by the Multiple Myeloma Research Foundation have had great success with their tissue bank program in helping to accelerate the development of novel agents that treat a similar blood cancer,

multiple myeloma. This funding has had incredible results fast tracking research and development of targeted agents that extend the lives of MM patients. The Stanford School of Medicine has several virtual tissue banks that focus on lymphoma and other cancers. So we can conclude that (after much careful, thoughtful research and some debate) it was logical that the IWMF would follow a similar path to support the establishment of a tissue bank for WM research. When the IWMF explored funding such a project, Judith May, President of IWMF, said, "Its success depends on how willing WM patients are to donate blood and bone marrow for research." Today the project is progressing, but we need to step it up, we need more participants.

Participating in the IWMF Tissue Bank Study entails some effort on the part of patient-participants but only at intervals. Over all, it is easy to do. There are a few simple steps that require your active involvement and coordination. First, you should spend some time reading about the Tissue Bank Study first announced in the October 2010 issue of the *Torch*! See www.iwmf.com/services/torch.aspx Then follow the directions to **Step 1**, **Step 2**, and **Step 3** below.

Step 1: All WM patients and family members reading this article should complete the questionnaire located at <http://tinyurl.com/WM-Questions> Your comprehensive confidential data is very helpful and becomes an important part of the research sample. Family members are considered the "control group" and their data serves as a standard sample by which experimental observations are measured. Print this questionnaire, fill it out, and mail it per the instructions. Again, this is important because in this way our small group can produce meaningful, actionable data based on good samples.

Step 2: Participants must sign a consent form in order to enroll. The consent form is located at <http://tinyurl.com/WM-Patient-Consent> Print the consent form, read it over, and on page 10 you must initial certain items and sign and date.

Step 3: When the completed questionnaire and consent forms have been received at DFCI, you will be sent instructions for the collection of bone marrow and buccal (a scraping of cells from the inside of the cheek) samples. No extra bone marrow collections are required. Rest assured that bone marrow samples are collected only when a bone marrow biopsy is scheduled by your physician. The buccal cells will be collected only once. Collection kits and shipping instructions will be sent from DFCI.

That's all there is to it. Complete the questionnaire and consent forms now and send them to DFCI. Then, when you are scheduled to have your next bone marrow biopsy, you must remember about 10 days ahead of time to make the arrangements with DFCI to have a collection kit sent to your physician before the scheduled biopsy. This is not really very complicated. Your physician will take a small sample of

IWMF Tissue Bank Study, cont. on page 31



13 NEW MEMBERS JOIN BEN RUDE HERITAGE SOCIETY

BY LAURIE RUDE-BETTS, CHAIRPERSON OF THE BEN RUDE HERITAGE SOCIETY

In 2008 the Ben Rude Heritage Society was established to honor my husband Ben Rude, the second IWMF President, and his leadership and legacy. One of the great things Ben would always do was to congratulate all of the members of the IWMF, because your participation indicates your deep involvement, both with the IWMF and with your own WM condition. Ben believed strongly throughout his life that *being involved* empowered you and made you feel less a victim and more a partner – with your WM, with your doctors who will help you manage it, and with the IWMF, which is leading the way not only to more successful management of your life with this orphan disease but, most importantly, to a cure. Fortunately, we have seen great progress as a result of research that is funded to a great extent by...us! This progress only makes us impatient for more!

We have 31 members already committed in the most meaningful way – through the Ben Rude Heritage Society – to the progress we desperately need. These generous people, our friends, have provided for continuing support for the IWMF through bequests, gift annuities, trusts, insurance policies, and similar planned gifts. In 2008, after Ben passed away, the Society was launched with over a quarter of a million dollars in gifts to remember Ben and get us closer to a cure. In only four short years, that number has quadrupled – to \$1,639,804! Clearly, people see what a gift like this means and will do for the Foundation.

At the Philadelphia Ed Forum this past June, we inducted 13 new participants to the Ben Rude Heritage Society. This was our largest group of new members since our inaugural year. It was such a gratifying moment! Let me tell you just a little bit about our new members individually:

Gregory Fitzwater and Marilyn-Zollner Fitzwater: Marilyn was diagnosed in 1998 and was scared not only by her initial diagnosis of a disease she could not pronounce but also by the lack of information for WM patients. She heard about Arnie Smokler, the founder of the IWMF, and was so relieved to find the support she was looking for. You probably read her story in the April issue of the *Torch*. Marilyn and Gregory have included IWMF in their estate plans, for which we are very grateful.

Penni Wisner: Penni, the IWMF Support Group Leader for 10 years in the California Bay Area, continues to write the very popular “Cooks’ Happy Hour” articles featured in the *Torch* and to edit the column Support Group News. Penni made the decision to designate the IWMF as the beneficiary of her IRA. We thank Penni and look forward to many more delicious ideas from our kitchen-meister in the years to come!

K. Edward Jacobi and Katharine McCleary of Little Silver, NJ: Ed, a retired probate attorney, was diagnosed in 1994. Katharine, a retired chemistry instructor and chemical engineer, actually suspected Ed’s Waldenstrom’s and amyloidosis before the diagnoses were made! Ed has chaired his local planning board for twenty years and is very active

in his church on both local and state levels as President of the New Jersey United Methodist Foundation. Ed and Katharine love to travel and have visited 30-odd countries, with Russia, Jordan, and Scotland at the top of their lists. They have two daughters and four grandchildren, three of whom live in Hong Kong. Ed and Katharine have designated the IWMF as a recipient under their wills.

We have several IWMF Trustees and their spouses who have also joined the Ben Rude Heritage Society this year: **Judith May, Michael Luttrell, Carl Harrington, Cindy Furst, Sue Herms, Guy Sherwood** and **Don and Mary Brown** have all included IWMF as a bequest or as a recipient of their insurance policies or IRAs.

Sue Herms has been a Board member for three years. Sue is chair of the Publications Committee and a member of the Research Committee. She oversees the publication of the IWMF booklet series and sees to it that they are revised to keep apace with the latest research. She is associate editor of and regular contributor to the IWMF *Torch*. Diagnosed in 2004, Sue found the IWMF through the Internet and joined IWMF-Talk. Sue is grateful for the opportunity she has had to learn about WM from our website, the Ed Forums, and IWMF-Talk, as well as for the support she has received from you, her many IWMF friends. She has designated the IWMF as a recipient in her will.

Cindy Furst has been an IWMF member for seven years and was a Board member for four. She was diagnosed in 2004 and is coordinator for our many support groups, providing valuable assistance to our wonderful support group leaders. She recently stepped down as Trustee to focus on her favorite retirement activities: golfing, hiking, and bicycling. Cindy has designated the IWMF as a beneficiary of her IRA.

Don Brown was diagnosed in 2002. He has been an IWMF Board member for four years and is a very active member of the IWMF fundraising team, as well as serving as a support group leader for the Chicago area. **Mary Brown** volunteers in many capacities for the IWMF, including “supporting the support group.” Don and Mary have designated the IWMF as a recipient of their IRA.

Carl Harrington has been an IWMF member for six years and a Board member for two. He serves as our Vice President for Fundraising and sits on the IWMF Executive Committee. Carl, who was diagnosed in 2006, has designated the IWMF as a beneficiary of his life insurance policy.

Dr. Guy Sherwood has been a Board member on and off for many years. Guy was diagnosed in 2001 at the young age of 40 and almost immediately became involved in the IWMF as an active IWMF-Talk member, writer of numerous *Torch* articles, information pamphlets, patient-centered booklets, and as a busy IWMF Trustee. He currently chairs the IWMF International Committee and is a member of the IWMF Research Committee – an amazing commitment of time and

13 New Members Join Ben Rude, cont. on page 31



ED FORUM 2012

BY SECRET WALLIE

Secret Wallie did it again! Attending the Ed Forum incognito, SW kept IWMF-Talk abuzz with nearly simultaneous reporting of events as they unfolded. Wallies who could not be in Philadelphia were able to hear of the advancements in WM research, learn more about the newest treatments, and share in the social side of the Forum – all thanks to Secret Wallie. The following excerpt from Secret Wallie's account provides a sense of the event's dynamics. For detailed and specific coverage of the major presentations, please refer to the Ed Forum DVDs and the Ed Forum Review, a summary of the major presentations, now online at iwmf.com in pdf format.

Note below that, as applicable, the pages are indicated where the summary of a specific presentation can be located in EFR (Ed Forum Review 2012).

Day 1: Friday, June 1

Friday morning began bright and early with breakfast at 8 am. Right away we were alerted to the opportunity of participating in two separate clinical studies – by donating buccal (cheek) cells (via mouthwash rinse) to Dr. Ghobrial's Tissue Bank Study (funded by the IWMF) and by donating tissue cells (via spitting saliva into sanitary containers) for Dr. McMaster's NIH Genetic Susceptibility Study.

Genetics and peripheral neuropathy were the topics of the opening presentations:

Dr. Brian Van Ness, Ph.D., University of Minnesota: "Genomics 101." *EFR* page 11.

Mary L. McMaster, M.D., National Cancer Institute: "Family Studies in WM." *EFR* page 16. Dr. McMaster urged attendees to find time to register for the study and provide samples during the Forum.

Michelle Mauermann, M.D., Mayo Clinic: "Peripheral Neuropathy in WM." *EFR* page 5.

These "early bird" sessions were followed by a buffet lunch, and then came separate tracks of breakout sessions for newly diagnosed patients and for veteran patients (and caregivers also!).

On the newly diagnosed track we had:

Robert Kyle, M.D., Mayo Clinic: "Understanding WM and Your Blood Tests." *EFR* page 1.

Peter Martin, M.D., Weill Cornell Medical College: "Choosing a Clinical Trial." *EFR* page 9.

Ron Yee and Bill Paul also shared their advice for new patients, and Nancy Zieber spoke about how to talk to your doctor and how to deal with the side effects of chemotherapy.

On the WM veterans' track:

Clinical trials veteran Jack Whelan spoke about his own experiences while offering guidelines from a veteran's perspective on participating in trials. Jack's account included a number of very amusing (not to say hilarious) anecdotes, and his audience heartily agreed with his pronouncement that humor is an important tool in disease management. In other sessions Connie Paul offered tips, guidance, and valuable information for caregivers; Guy Sherwood addressed best practices for approaching pain management; and Dave Benson was on hand to advise WMers about gifting and estate planning options.

A welcome break came next with a tasty choice of munchies and beverages to sustain us for the two final items for the day in a joint session:

Dr. Stephen Ansell, M.D., Ph.D., Mayo Clinic: "Factors Regulating IgM-Producing B-Cells." *EFR* page 17.

Mitch Orfuss, Karen Lee Sobol, and Jack Whelan concluded the session, sharing their experiences as patient veterans. All three of these fellow IWMF members have had very good outcomes when they participated in clinical trials.

Friday evening's festivities began with the President's Reception. Folks in attendance partook of appetizers, drinks, and good company. A small group of IWMF-Talkers was tucked away in a corner making efforts to match faces with familiar IWMF-Talk names. It was great to see Jeff Atlin looking so healthy after his very recent stem cell transplant and to be able to thank him and his wife in person for sharing their experience with all of us!

The capping event of the day was the Ed Forum Dinner, where IWMF President Judith May officially welcomed everyone to the Ed Forum and gave appropriate recognition to the many volunteers who helped put the Ed Forum together. Judith encouraged everyone to enjoy the Forum and the dinner! Trustees Ron Yee and Carl Harrington served as the "unofficial mayors" of Philadelphia and treated everyone to a creative multimedia presentation of interesting *phacts* about Philadelphia (they taught us to use the local custom of substituting *ph* for *f* when spelling) and tips on interesting sights to see in *Filadelphia* (oops! I mean *Philadelphia*). The evening ended with our keynote speaker, Charlie Lustman, a professional musician-singer-songwriter who has survived rare cancer of the jaw and now makes it his mission to spread the word that living with cancer can be more than just surviving if one aims at thriving! His emotional, genuine, and heartfelt presentation included stories about his own

Ed Forum 2012, cont. on page 6



personal experiences, lessons he has learned, and songs he has written about facing cancer diagnosis and treatment. He truly was an inspiration to all!

Day 2: Saturday, June 2

The day began with yoga for the very early risers at 6:30 am (OK – I had the best of intentions but just couldn’t make it!) and a hot breakfast for all – where one could find patients sharing stories and breaking bread with researchers. Patient and caregiver volunteers were already at the registration table (as they were all day, every day – it was wonderful to see their smiling faces and just to have them there to answer questions and help their IWMF “family members,” especially those new to the IWMF and to the Ed Forum). The area around the registration table was bustling with the folks from Dana-Farber collecting tissue samples from volunteer patients, also folks from the NCI-McMaster Familial Study collecting information and saliva samples from volunteer patients, Karen Lee Sobol offering, for a small donation, autographed copies of *Twelve Days*, her personal account of her journey from WM diagnosis to cure (and her personal philosophy on how to approach life), volunteers handling attendee registrations, and raffle tickets being sold for the fantastic WM quilt.

A lot of information was presented today, and, I have to admit, my relatively “unscientific” mind was overflowing with amazing bits of information by the end of the day! We are truly fortunate to have such intelligent, motivated, and amazing researchers working on our behalf. Just running down the list of those who spoke on Saturday and their topics leaves little doubt that we are at a stage where our knowledge of WM is rapidly increasing. I will again remind you that viewing the Forum DVDs and reading the *Ed Forum Review* summaries are the best ways to recapture all that was conveyed to us from the podium. Here’s the line-up for the morning:

Dr. Brian Van Ness, Ph.D., University of Minnesota:
“Genomics and Personalized Medicine for Cancer.”
EFR page 13.

Dr. Rafat Abonour, M.D., Indiana University School of Medicine: “WM: Is There a Role for Transplantation?”
EFR page 7.

Irene Ghobrial, M.D., Dana-Farber Cancer Institute: “Updates on the Biology and Therapy of Lymphoplasmacytic Lymphomas.” *EFR* page 22.

Saturday’s luncheon was a sit-down event, the ballroom filled with excited chatter as folks had a chance to meet new table-mates (and future friends!) and compare notes on the morning’s presentations – until Judith May took the podium to thank by name the many volunteers who work so diligently year round for the IWMF and those who were making the Forum run so smoothly. Laurie Rude-Betts followed next to introduce the new members of the Ben Rude Heritage Society, generous individuals who have included the IWMF in their estate planning. (You will meet these new members on page 4 of this issue.). Lunch ended with the drawing for

the magnificent WM quilt (generously donated by Marilyn Zollner-Fitzwater, who won the raffle at a previous Ed Forum and enjoyed displaying the quilt for a number of years). This year the lucky ticket was held by Annette Aburdene – and as the winner’s name was announced at the end of lunch, everyone rushed out the doors to secure their seats for the afternoon’s session. Back to business! The next round:

Steven P. Treon, M.D., Ph.D., Dana-Farber Cancer Institute: “Genetic Basis of WM Revealed by Whole Genome Sequencing.” *EFR* page 23. Dr. Treon presented information regarding his whole genome sequencing research (partially funded by the IWMF) in such a way that helped make the science of whole genome sequencing a bit more understandable for the lay person (like myself, for example!). Here’s some of the information he provided: of the 3 billion DNA molecules in a cancer cell, the MYD88 L265P mutation that he found via paired sequencing was in *one* of those molecules; of the WM patients he studied, the MYD88 L265P mutation was found in 91% (49 out of 54 patients); the MYD88 mutation was also seen in 3 of 3 LPL patients, in 2 of 21 MGUS patients, and in none of 15 healthy patients also studied. Dr. Treon further noted that rheumatologists have been developing drugs to inhibit MYD88 (incidentally, he pronounced MYD88 as “mid-88”) for many years, and this may lead to new treatment possibilities for WM. Once again, the Forum DVDs and the *Ed Forum Review* summaries will tell you more.

Recipients of Joint IWMF-LLS Grant to Develop New WM Cell Lines (Anne Novak, Ph.D., Mayo Clinic; Asher Chanan-Khan, M.D., Mayo Clinic; Irene Ghobrial, M.D., Dana-Farber Cancer Institute): “Cell Line Panel.” *EFR* page 18.

Morie Gertz, M.D., Mayo Clinic: “Overview of Current Therapies.” *EFR* page 3.

The last two sessions of the day put me over the top in terms of my brain being chock-full of fascinating information:

Anne Novak, Ph.D., Mayo Clinic: “Lymphoma Genetics.” *EFR* page 20.

Edward A. Stadtmauer, M.D., University of Pennsylvania: “Cellular Therapy and Stem Cell Transplant for WM.” *EFR* page 10.

The Forum adjourned on Day Two at 5 pm, with the evening free for folks to either partake of a buffet type dinner that was available in the restaurant or to take a short public transit ride into downtown Philadelphia for sightseeing and dining. One could see folks gathering in the meeting room hallway and arranging to have dinner with their new-found “brothers and sisters” with whom they could share personal treatment experiences and life experiences, and just let their thoughts and feelings pour out, knowing that the person hearing it

Ed Forum 2012, cont. on page 8



AN ED FORUM ALBUM: PHILADELPHIA 2012



would understand exactly what they are going through. Sharing such experiences with a fellow Wallie, whether he or she is from the next city or on the other side of the world, is truly a cathartic and calming experience.

Day 3: Sunday, June 3

The day began once again with yoga for the early risers (and again my intentions were the best but...). A restorative hot buffet breakfast was available for all, and one could see folks again sitting at tables with other attendees, with IWMF Board Members, and with the doctors and researchers who made presentations during the weekend.

The last morning of Ed Forum 2012 opened with the latest version of a performance that has become an IWMF classic: the “Garden Talk” by Dr. Morie Gertz of the Mayo Clinic. For some years a DVD filmed in 2003 has been in circulation and available through the IWMF. Every year a repeat performance is requested for the Ed Forum, and this year Dr. Gertz agreed to present an updated version of the talk in order to film a



Dr. Morie Gertz reprises “The Garden Talk.”

new DVD of better quality. Displaying his creative talents, Dr. Gertz stood on the stage next to a flip-chart and began drawing two large circles, one inside the other, to represent the bone marrow. He then embarked on an explication of his metaphor of our marrow as comparable to a garden – a garden where both nourishing vegetable plants and noxious weeds can grow but where, when overgrown for some (like us), the weeds threaten to choke off the good plants.

As he spoke, I began to recall the first time I watched the “Garden Talk,” and I remembered how Dr. Gertz stressed at that time (eight years ago) the fact that our choice of treatments was so limited (our “silver bullets” he said) that he cautioned us to use each of them carefully and sparingly. Well, compare what was then and what is now. Yesterday Dr. Gertz gave us a comprehensive overview of the most current therapies in use

to treat WM, starting from the days when plasmapheresis was the only way to control our disease up to today when there are many new drugs and combinations to choose from. Dr. Gertz also explained how our disease status may influence the decision of which drug to turn to when treatment is needed. Thinking back to yesterday, I realized that the overview we heard then from Dr. Gertz amounts to the full list of possible products we now have to select from when we go out to buy something to decimate those weeds in our garden. And he no longer stresses how limited the choices are!

I can’t possibly do his presentation justice and so I’ll refer you to the new DVD of this talk – of good quality and soon available.

The Ed Forum program always closes with the much-anticipated “Ask the Doctor” session. Throughout the weekend, as folks hear various presentations, invariably a question or two arises about a concept they’d like to hear more about, but there just isn’t time to ask the doctor during or after his or her presentation. So folks are encouraged to write down their questions on index cards, which Dr. Robert



The 2012 “Ask the Doctor” panel: from l. to r., Dr. Morie Gertz, Dr. Edward Stadtmauer, and moderator Dr. Robert Kyle.

Kyle (the “godfather” of WM, so to speak) reads early Sunday morning, categorizes their subject matter, and then selects the questions to ask the doctors. This year we had a fantastic compilation of expertise and knowledge with Dr. Morie Gertz and Dr. Edward Stadtmauer on the panel and Dr. Kyle at the podium. But don’t just take my word for it when you can experience it for yourself on the Forum DVDs!

Actually, there is one more session after the “Ask the Doctor” panel, and that is the IWMF Annual Report to the Members. This is the opportunity for your hard-working IWMF Board of Trustees to show the membership what they’ve been doing during the past year and what they plan to do in the future on behalf of *all* members regarding education, support, and research. It’s also the occasion for members to understand the tremendous efforts put forth by a select number of



fellow patient-volunteers. These fellow patients do not take on their roles for financial remuneration or for recognition – they do it because they are caring individuals who have the talents and the time to reach out to fellow patients in their own unique way, and they are to be commended for it. There were reports from our President Judith May and from the various committees – publications, research, finance, member services/website, international, scientific advisory (headed by Dr. Kyle). At the end, the Board members asked for thoughts and recommendations from the audience.

The Annual Report is an important event for the strength of the Foundation, and I really urge attendees in the future to arrange to stay and participate in this closing event – this could be an even more interesting meeting in the future if more members were to attend.

Before signing off I really must mention the great job done by IWMF office manager Sara McKinnie and staff in preparing for the event, coordinating volunteers to assist in the registration and other activities, and ensuring that every

aspect of it ran smoothly. Also, most of the sessions were recorded, and the A/V speaker system and lighting were managed by patient volunteers with the IWMF's equipment. Our volunteers were Michael Luttrell and Terry Rossow, and their tireless efforts throughout the entire Ed Forum ensured that all sessions went off perfectly.

So, another year's event has come and gone for Secret Wallie, who enjoyed yet another wonderful Ed Forum and attempted to take diligent notes and relay the events back to IWMF members who were unable to attend. I now look forward to next year in San Diego, CA – to the opportunity to learn about more new advancements in the treatment and cure of WM and another reunion with fellow IWMF family members – patients, caregivers, and researchers.

I must admit that I'm missing my IWMF family members already!

Until next year!

MY COMFORTER: IMPRESSIONS OF A NEWBIE

BY MARILYN BAGEL

"Mom, don't sugarcoat it. Tell me everything. What do you mean you have a blood abnormality?" That was the reaction from our 23-year-old daughter as I began to explain my Waldenstrom's diagnosis.

My immediate response was, "I'm still trying to sort it all out myself."

Thanks to the information on the IWMF website as a guide, I began to go into greater detail.

I've always been a joiner, but the IWMF is one "club" I never thought I'd be a member of. When I first learned of my diagnosis in November 2011, I went on the web and was horrified at what I came across – until I found the Foundation website. A great source of information and comfort, the website helped me stop panicking, regain my composure, and develop a game plan. I followed its wise advice – take charge of my medical team. Thanks to the list of consulting specialists, I was able to link Dr. Treon with my local oncologist/hematologist.

I also knew I was not alone. There was great comfort in that. With the Educational Forum coming up in Philly, I was encouraged that it too would deliver on all counts. I was not disappointed.

My husband accompanied me. As we made the drive to Philly I had a mixture of hope and trepidation. After all, this was an all-new experience. Since I had no frame of reference, I also had no specific expectations.

What I learned: camaraderie = comfort. Surrounded by a ballroom full of those with my diagnosis, like a cozy quilt, the Educational Forum became my comforter.

With it wrapped around me, I was able to take in what was truly an impressive series of medical presentations. As I attended the various sessions, I thought about how extraordinary it is to be sitting among so many people sharing the same rare illness along with the medical experts who are at the forefront of researching our disease. They addressed every aspect of our illness. That was comforting in and of itself. The genetic aspects were especially enlightening. Though we share the same disease, I am also continually struck by how vastly different our array of symptoms can be.

As a newbie, much of the information came in waves that at times submerged me. I tried to absorb as much as I could. As for the rest, I just let the tide roll over me, knowing I would periodically come up for air.

Helping me do that was the breakout session for new patients, which I attended while my husband went to the one for caregivers. We were both impressed.

Meanwhile, I couldn't help but notice that, throughout the Forum, surrounding me were people who all knew our Wallies' secret code. This crowd needed no explanation about IgM, IgA, IgG, MGUS, CHOP...Hemolysis, Plasmapheresis, and W&W. The last three sound like the name of a law firm.

My Comforter, cont. on page 32

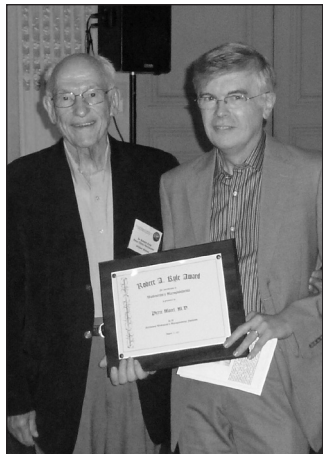


SEVENTH INTERNATIONAL WORKSHOP ON WALDENSTRÖM'S MACROGLOBULINEMIA

BY GUY SHERWOOD, M.D., IWMF TRUSTEE

The Seventh International Workshop on Waldenström's Macroglobulinemia (IWWM7) was held August 23-26 in Newport, Rhode Island, USA. This bi-annual scientific conference for WM, by far the most important scientific event for WM, was attended by a record 250 individuals from all over the world. One may recall that the First International Workshop on WM was held at the National Cancer Institute in Washington, D.C., in 2000 and was attended by a mere 19 investigators! Since this historic first conference, there has been increasing attendance at the workshops in Athens (2002), Paris (2004), Kos Island, Greece (2007), Stockholm (2008), and, most recently, Venice (2010). The IWMF was a key supporter of the first workshop in Washington and has continued its support of all the successive international workshops.

Following closely the format of the 2010 IWWM6 conference in Venice, Italy, the number of lecture sessions, debates, poster presentations, consensus panel discussions, as well as a special guest presentation (by Dr. Bruce Cheson – director of the very first IWWM meeting in Washington, D.C., in 2000) resulted in a very busy and comprehensive conference.



Dr. Pierre Morel of France, recipient of the Robert A. Kyle Award, is shown here with Dr. Kyle following the IWWM7 Opening Ceremonies.

As is customary at these impressive conferences, researchers who have made outstanding contributions in the field of WM were recognized at fabulous evening events. Dr. Pierre Morel of France was honored with the Robert A. Kyle Award at the IWWM7 Opening Ceremonies held at the historic Rosecliff Mansion. At the Closing Ceremonies at the historic Marble House, the prestigious Waldenström Award was bestowed upon Dr. Véronique Leblond, also of France.

The lecture sessions, comprised of a number of 15-minute presentations by world experts, included topics such as



Dr. Véronique Leblond, also of France, received the prestigious Waldenström Award.

pathological challenges in WM diagnosis, genetic predisposition to WM, cell origin and genetic basis of WM, molecular pathogenesis in WM, microenvironment and immune interactions in WM, novel therapeutic approaches to WM, primary treatment of WM, salvage treatment of WM, special topics in the treatment of WM, and finally response assessment in WM. Perhaps the most anticipated sessions were the consensus

discussions on treatment options in WM and response criteria in WM.

Despite the beautiful environs to be found around Newport, despite the spectacular events held in the evenings, nothing could quite compare to the “buzz” generated by Dr. Steven Treon’s presentation of his team’s remarkable scientific achievement: the delineation of a very specific MYD88 L265P genetic mutation found in 90% of WM patients – an amazing finding with far-reaching implications. Following Dr. Treon’s exciting presentation, and throughout the remainder of the conference, one could hear repeatedly comments such as “outstanding data,” “a new era,” “we will never forget this day,” and my personal favorite – “cure.” I must admit to being quite impressed with the potential implications of this impressive research and could not help but feel happy for the dedicated researchers who have worked so very hard for many years in Dr. Treon’s lab.

Another conference highlight (of which there were many) was the quiet realization that researchers were finally beginning to fit the many pieces of the very large and confusing cellular pathways puzzle that exists in WM. What had at one time seemed to be an endless array of independent and complicated series of cascading bio-molecular pathways has now slowly begun to be inter-connected thanks to the quality work done

Seventh International Workshop, cont. on page 30

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



PRESENTING EMIL PARENTE: LIVING WITH WM FOR 32 YEARS

AS TOLD TO SUE HERMS

Emil Parente is a WMer with a real past, and he is happy to share it with others, particularly those who are newly diagnosed. After all, Emil is special – he was diagnosed in 1980 at the relatively young age of 50 and is still doing very well after all these years. He wants others with WM to take heart and hope from his WM journey.

At the time of Emil's diagnosis, he was working as a senior executive for Fluor Corporation, the world's largest publicly-owned engineering/construction company, and was required to have an annual company physical. Blood tests indicated that



Emil Parente, WM survivor of 32 years, poses with his "two darling granddaughters" Gianna (3) and Kira (9).

he had a high erythrocyte sedimentation rate (ESR), and he was referred to a specialist to determine the cause. When Emil arrived at the specialist's office, he discovered that the doctor's specialty was oncology, and he began to realize that he might have a serious problem. After a bone marrow aspiration, the doctor provided a preliminary diagnosis of multiple myeloma,

but another physician indicated that it was Waldenstrom's "syndrome" instead (as it was referred to then). At that time not much was known about WM. The doctor who confirmed Emil's WM diagnosis suggested that Emil might want to see Dr. Jan Waldenström in Sweden, but he decided not to go – a decision that in hindsight Emil now regrets because he missed the opportunity to meet such an important physician in the history of WM.

Emil's biggest concern about his cancer diagnosis was one that many cancer patients can identify with – he had an 8 year old daughter and a 5 year old son, and he was understandably worried about their futures. In 1980 no one could really answer his questions about life expectancy, so Emil made a conscious decision, as he says "not to obsess about his disease but rather to fight it, with as few chemotherapy treatments as possible, and to live life normally while doing so." Emil still has a copy of the first article he read in 1988 about WM life expectancy, published by the University of California-San Francisco, which stated that "the median survival [of WM patients] is about 50 months". Since Emil had already passed that mark by the time he read the article, he feels to this day that his decision has been the right one.

In 1982, Emil went to Dr. Stephen J. Forman, a hematologist at City of Hope, and has remained with Dr. Forman ever since. Dr. Forman's philosophy has been to treat symptoms

and not numbers; consequently, Emil was on watch and wait and did not begin treatment until 1985, when his IgM and serum viscosity reached the point of concern about possible ill effects from hyperviscosity syndrome. At that time, there were basically only three treatments for WM, chlorambucil (Leukeran), prednisone, and plasmapheresis (PP). Dr. Forman started Emil on chlorambucil.

Even with chlorambucil, Emil's IgM production required regular PP treatments to keep it under control. Since chlorambucil proved to be ineffective, Emil has since used PP as his primary "line of defense" against WM and he believes that PP is somewhat under-utilized in the management of WM. In fact, Emil has had 189 PP treatments, or as he calls them, "oil changes," since his diagnosis. He experienced a serious spike in his IgM in 1991 and began a series of five cladribine (2CdA) treatments. At that time, cladribine was in clinical trials for hairy cell leukemia patients, and Emil believes that he may have been one of the first WMers to receive it. In any case it brought his disease under control, and with continued PP he remained stable until 2002.

Another spike in IgM production led Emil to try solo Rituxan therapy in 2002, but he didn't receive any measurable benefit from it, so he began combination Cytosan/fludarabine/Rituxan treatment in 2003. He was originally scheduled for six cycles, but after four cycles the antibiotic he was taking to prevent infections during treatment led to overgrowth of a dangerous intestinal bacterium called *Clostridium difficile*, the effects of which landed him in the hospital for a short period. Other than that, he has not been hospitalized for WM-related problems. Following that experience, Emil resumed PP as his only treatment.

Because of recent periodic sinus and ear infections (with some hearing loss), Emil has added regular intravenous IgG as part of his regimen. This spring, he was again experiencing higher IgM levels and began contemplating a decision to pursue another treatment. At the advice of Dr. Forman, Emil chose six cycles of bendamustine, administered for two consecutive days every four weeks. Rituxan will be added as his IgM decreases in order to avoid a potentially dangerous IgM flare. While Emil is experiencing some fatigue and gastrointestinal upset, he is encouraged that at the end of his second treatment cycle, his IgM has gone from 5,000 to 4,000. He is hoping that this therapy will greatly reduce his need for periodic plasmapheresis.

Over the years, Emil has seen a big improvement in treatments for WM, as there are now many more options available than there were in the 1980s. The process of plasmapheresis itself has also changed. When Emil first began PP, it was a batch process vs. the continuous process utilized today. Then a

Presenting Emil Parente, cont. on page 32



PSYCHOLOGICAL AND SOCIAL NEEDS OF THE CANCER PATIENT: THE SCOPE OF THE PROBLEM

BY WANDA HUSKINS, IWMF MEMBER

"I was told I had a potentially fatal disease. Now that gets your attention. The Big C. The word "cancer." It overwhelms the psyche – just the word. I couldn't believe it. I was unprepared for the enormous emotional jolt that I received from the diagnosis."

– Sandra Day O'Connor, former US Supreme Court Justice and cancer survivor

Addressing the Psychological Needs of the Cancer Patient

Cancer is widely considered the most feared of all diseases. A diagnosis of cancer triggers an acute stress response in most people. Generally, shock and disbelief are the first reactions to this dreaded disease, but soon a cascade of fear and uncertainty clouds the mind of the newly diagnosed. The subsequent stress of learning that one has a cancer, and in our case an incurable cancer, creates considerable emotional turmoil for the patient, family, and caregiver. But this crisis state is actually normal and quite common, varying only with the intensity felt by the individuals involved. Our minds try to make sense of a diagnosis that initially seems so unfathomable. We become cognitively confused and, literally, do not know how to process the information we are hearing. An anxiety state can appear after the initial shock and may manifest itself with insomnia, loss of appetite, ruminating, difficulty concentrating, and irritability.

Typically, this crisis period will subside in one to several weeks as the resilient mind seeks to de-emphasize this threat to our life, and we begin to adjust our thoughts to face our new situation. During this period of upheaval the newly diagnosed often find the strength and support they need from family and friends. Additionally, the treatment team can play a huge role in offering hope and support when a course of action is determined. In time a vague sense of calm will emerge as we gently repeat to ourselves: "It will be OK."

We can expect the intensity of this initial shock to subside, but, as with any life-altering event, our cancer will continue to challenge us emotionally and socially even as we take steps to adjust and protect our cherished way of life. When cancer arrives it brings with it a message of change and loss resulting in emotional hardship that can be felt in the entire family network and the community at large. We perceive ourselves differently as we imagine potential or actual losses we face. Cancer and its treatments can cause loss of independence and vitality, diminished self-confidence, loss of career advancement, unfulfilled ambitions, relationship problems or sexual inadequacy, and isolation. Because we also feel a loss in our life expectancy we feel the need to re-evaluate the plans, aspirations, and dreams for the future

we had imagined before a cancer diagnosis. Predictably our distress level will ebb and flow as we coexist with our cancer and live with its uncertainty. After the crisis of "this *can't* be happening" we enter into the reality of "it *is* happening."

Patients and their families can be expected to experience a normal range of psychological concerns in the face of living with cancer, but many will be at risk for abnormal levels of distress and despair which then become problematic and further impact their quality of life. The cancer experience can bring on emotions that may feel overwhelming at times. Whether we are coping with the initial diagnosis, the rigors of our treatments, the nagging worry over reoccurrence, or the concerns for our family and our financial situation, we will continue to be tested both by the cancer and by its ramifications. Understandably we feel sadness and grief along with frustration and anger. For some patients this frustration and anger – which are normal feelings and reactions – can and do intensify. They can even intensify to a disturbing level. Life for these cancer patients will become dysfunctional and bleak.

It is estimated that as many as 35-50 percent of cancer patients in the USA are afflicted by psychological problems.¹ The inability to adapt to the changes that their cancer presents is most frequently observed with cancer patients afflicted with psychological problems. Inability to adapt falls under the diagnostic classification of an adjustment disorder. The anxiety felt will become severe and barely tolerable. Patients with severe anxiety complain of constant tension and appear restless and hypervigilant. They complain of insomnia, poor appetite, apprehension, and will worry and brood. Sometimes sadness may evolve through a continuum resulting in a "situational" major depression, precipitated by a stressful life event. Feelings of hopelessness, worthlessness, excessive guilt, loss of self-esteem, and anhedonia (inability to experience pleasure) are the hallmarks of a major depression. An agitated depression may also occur when symptoms from both a depressed mood and an anxiety disorder overlap. Current research also explores the cancer experience as a cause of post traumatic stress disorder (PTSD) in vulnerable individuals.

Cancer patients at greatest risk for a mood disorder are those who are susceptible to depression and stress, are more clinically advanced, have more disability and or disfigurement, or are in unrelieved pain. Familial cancers also increase the likelihood of a higher stress reaction as patients may have witnessed repeatedly the effects of cancer on loved ones. When severe mood disturbances do happen they can adversely affect the

Psychological and Social Needs, cont. on page 32



IMAGINE THIS: FROM RITUXAN PROJECT TEAM TO PATIENT

BY TOM WHITE, IWMF MEMBER

During the many years that I worked on the product Rituxan, I can honestly say the thought never crossed my mind that I would actually become a blood cancer patient on a Rituxan regimen.



Tom White at the Genentech campus where for many years he was a member of the team that developed Rituxan, a drug so familiar to us all.

Work on the Rituximab Core Team

It all began in 1971 when, armed with a BS in Chemistry and an MBA, I began my career at Cutter Laboratories (soon to be acquired by the Bayer pharmaceutical company) which produced IV solutions and the products of blood fractionation. At Cutter I gained my grounding in finance and operations management, as well as in the healthcare industry itself. Ten years later, in 1981, I decided to leave the pharmaceutical industry and take a gamble with a small fledgling startup named Genentech and the new promise of biotechnology.

Biotechnology differs from the pharmaceutical industry. Pharmaceutical companies create chemical compounds to fight disease, and they harvest proteins and other natural compounds from the human body and package them for use in patients who are deficient. Biotechnology focuses on cloning and mass-producing these and other naturally occurring compounds with the aim of using the body's own defense mechanisms to fight disease. Manufacturing such products avoids the potential shortages and contaminants or mutations that can occur when production is dependent exclusively on human sources.

At Genentech, after several years in finance, production planning, and logistics, I moved into the area of collaborations. In this role I was responsible for establishing relationships with companies that would either help Genentech manufacture products or that would be responsible for marketing Genentech's products outside the United States. In 1997 I was appointed to a new senior team, the Rituximab Core Team.

The development of Rituxan was a joint collaboration between Biogen-Idec and Genentech. Biogen-Idec discovered the antibody protein rituximab, and Genentech was responsible for its manufacture and commercialization as Rituxan. The Rituximab Core Team's prime responsibility was to gain FDA approval for Rituxan and determine the focus of future clinical trials, patient needs, and, ultimately, manufacturing needs. I represented manufacturing and process development and negotiated with our foreign partners who would provide Rituxan outside the United States. My primary focus following initial FDA approval of Rituxan (and for the next eight or so years) was to help gain approval for Rituxan in countries around the world and to ensure that we could make adequate amounts of Rituxan to meet all worldwide needs.

To understand the huge quantity of Rituxan antibody required to meet these worldwide needs, consider, for example, how Rituxan works in the case of WM. As a monoclonal antibody to CD20, rituximab binds to the protein CD20 that is present on the cell surface of B-lymphocytes, including the malignant WM lymphocytes. Once bound, the Rituxan antibody can then kill the lymphocyte directly or enlist the body's own immune system to do the job. However, because there are so many B-lymphocytes and because they are produced continuously, vast amounts of the Rituxan antibody must be infused to bind each of these CD20 sites. Because of the need for significant supply, the manufacturing process at Genentech had to be scaled up, and a new manufacturing facility had to be built and FDA approved.

Once the worldwide approvals were in place, the need for Rituxan exceeded original plans, and as a result much time was spent negotiating with Idec and international partners and carefully allocating inventories to ensure no patient went without needed product. New production facilities were next planned and constructed. In addition, much effort had to be spent on developing a more productive cell line which could produce considerably more Rituxan per batch. Further FDA and worldwide approvals were required as we went forward.

Exposure to patients

As the going gets rough with the complexities of dealing with partners and meeting tight deadlines for plant construction and FDA approvals, nothing is more inspirational in spurring your job efforts than hearing a patient's testimonial. On the Genentech campus many banners bearing the faces of our patients hang from buildings to remind us of our mission. In addition, our project team would invite patients with non-Hodgkin's and other lymphomas to general campus meetings to recount how Rituxan helped prolong their lives.

Imagine This, cont. on page 34



MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE

Mayo Clinic Reports Long-Term Results on Progression in Smoldering WM – Mayo Clinic has reported long-term results on progression in smoldering WM. Smoldering WM is defined by the presence of serum IgM ≥ 3 g/dL and/or $\geq 10\%$ bone marrow lymphoplasmacytic infiltration but no evidence of end-organ damage that can be attributed to the disorder. In this 20+ year study, the risk of progression of smoldering WM to full-blown disease was highest in the first five years after diagnosis (approximately 12% per year) and then 2% per year for the next five years. A median survival in excess of 14 years was observed. The standard of care for patients with smoldering WM should be close follow-up every few months without therapy. The pertinent laboratory tests should be repeated 2-3 months after initial recognition of smoldering WM to exclude early activity; if the results are stable, the studies should be repeated every 4-6 months.

Treatment Outcomes Reported for Bendamustine Therapy in WM Patients – Dana-Farber Cancer Institute published a study of treatment outcomes for 30 relapsed/refractory WM patients following bendamustine-containing therapy. Treatment for 24 patients consisted of bendamustine (90 mg/m²) on days 1 and 2 and rituximab (375 mg/m²) on either day 1 or day 2. Six rituximab-intolerant patients received bendamustine alone or with ofatumumab (Arzerra). Each treatment cycle was four weeks, and the median number of cycles was five. At best response, median serum IgM declined from 3980 to 698 mg/dL, and hematocrit rose from 31.9 to 36.6%. Overall response rate was 83.3%, and median progression-free survival was 13.2 months. Prolonged myelosuppression was more common in patients who received prior nucleoside analogue therapy.

PCR Method Developed to Detect MYD88 L265P Mutation – In an earlier study, Dana-Farber Cancer Institute identified a highly recurrent mutation (L265P) in the MYD88 gene in approximately 90% of patients. It has now developed a PCR (polymerase chain reaction) assay to detect the mutation and has evaluated this assay in a cohort of 99 patients. DNA from bone marrow aspirates was obtained, and 86% of WM patients were positive for the mutation by PCR. MYD88 L265P positive patients showed greater bone marrow involvement, higher serum IgM, and lower serum IgA and IgG levels vs. MYD88 L265P negative patients. It was suggested that this PCR assay can provide a simple and sensitive diagnostic tool for detection of the mutation.

Phase I/II Study Reports Results for BTK Inhibitor in CLL – The oral agent ibrutinib (PCI-32765) has been tested in a Phase I/II study of elderly patients with chronic lymphocytic leukemia conducted by the Ohio State University and MD Anderson Cancer Center. Ibrutinib is the first drug designed to target Bruton's tyrosine kinase (BTK), a protein

that is essential for B-cell survival and proliferation. With a median follow-up of 14.4 months in the 420 mg arm of the study, the overall response rate was 81%, and progression-free survival with 14.4 months of follow-up was 96%. The most common adverse events were diarrhea, nausea, and fatigue. Of the 31 patients on the trial, only one patient discontinued treatment due to disease progression.

Dana-Farber Cancer Institute Reports BTK Activation in WM Cells Facilitated by MYD88 Mutation – Dana-Farber Cancer Institute reported that BTK activation in WM cells is facilitated by the MYD88 L265P mutation and participates in downstream signaling of the NF-kappa B and MAPK pathways. Inhibition of BTK by PCI-327625 led to robust tumor cell killing of WM cell lines expressing the mutation and had a synergistic effect in the presence of IRAK 1/4 kinase inhibitors. This study provides a framework for the investigation of BTK inhibitors in WM.

Long-Term Data Available for Everolimus (RAD001) – Dana-Farber Cancer Institute and the Mayo Clinics in Rochester and Scottsdale presented long-term data from a Phase II trial of the oral mTOR inhibitor everolimus (RAD001) in relapsed or refractory WM. Sixty patients with relapsed/refractory WM were treated with daily 10 mg doses. The overall response rate was 73%, progression-free survival was 22 months, and overall survival was 55 months for the entire study population. The most common hematological toxicities were cytopenias, and pulmonary toxicity occurred in 5% of patients. Dose reductions due to toxicity occurred in 63% of patients.

Results Available for Phase II Trial of Enzastaurin – Dana-Farber Cancer Institute reported a multi-center Phase II clinical trial of enzastaurin in previously treated patients with WM. Enzastaurin is an oral serine/threonine kinase inhibitor. This study enrolled 42 patients and resulted in an overall response rate of 38.1%. One patient had grade 3 leukopenia and one patient died during the study from septic shock; both events were considered drug-related.

Total IgM and M-Spike Compared as Markers of Disease Status in WM – Changes in total IgM and the M-spike as determined by electrophoresis are both used as serum response markers in WM, but their ability to reflect disease status has not been compared. Dana-Farber Cancer Institute conducted a study of 73 patients who underwent rituximab-based therapy and for whom serial total IgM, IgM M-spike, and bone marrow biopsies were available for comparison. Their conclusion was that both serum IgM levels and IgM M-spike show similar correlations to changes in bone marrow disease burden; although overall the strength of these correlations is moderate, it is poor among patients with either low (< 1,000 mg/dL) or high (> 5,000 mg/dL) serum IgM levels.

Medical News Roundup, cont. on page 15



Study Analyzes Hypersensitivity Reactions to Rituximab – From 2006-2010, Massachusetts General Hospital analyzed hypersensitivity reactions to rituximab in patients with B-cell malignancies. Immediate reactions occurred in 9% of patients. A majority of these patients (76%) developed symptoms on their initial infusion; however 46% of moderate or severe hypersensitivity reactions occurred on subsequent infusions. Patients with moderate or severe reactions at their initial infusion were more likely to have a recurrent reaction. Advanced stage of disease increased the risk of a moderate or severe reaction. WM patients had a disproportionately higher risk as they accounted for 10% of all reactions even though they represented only 1% of patients treated with rituximab. All patients with complex hypersensitivity reactions who were referred for desensitization were able to complete therapy safely.

Phase I/II Results Reported for AME-133v Antibody Targeting CD20 – The University of Alabama at Birmingham reported results of a Phase I/II study of AME-133v in patients with previously treated follicular lymphoma. AME-133v is a humanized monoclonal antibody engineered to have better binding with CD20 on B-cells and to improve binding to the low affinity polymorphisms of the FcγRIIIA receptor on natural killer cells, which are thought to predict lower response rates and shorter duration of responses to rituximab. In Phase I, 23 patients were assigned to one of several dose escalation groups, ranging from 2-375 mg/m² weekly for four doses, and a partial or complete response was observed in 22% of patients with a median progression-free survival of 25.4 weeks. Common adverse events included chills and fatigue, and one patient experienced a dose-limiting toxicity of neutropenia. For the following Phase II trial, 44 relapsed follicular lymphoma patients received 375 mg/m² weekly for four doses. The overall response rate was 36%, and median progression-free survival was 91 weeks.

Study Concludes Certain Drugs Block Efficacy of Oral Cancer Therapies – A study conducted by Medco Research Institute and reported at the 2012 American Society for Clinical Pharmacology and Therapeutics Annual Meeting concluded that 23-74% of patients are taking oral cancer drugs along with other medications that may have the power to reduce the strength of the cancer drugs or increase their side effects. The oral cancer drugs include Gleeevec, Tarceva, Sprycel, Afinitor, Tykerb, Tasigna, Votrient, Nexavar, and Sutent. The medications that pose a threat to their effectiveness were calcium channel blockers, certain antibiotics, antifungal agents, steroids, and proton pump inhibitors.

New Antibody Targets CD37 on B-Cells – ImmunoGen, Inc. announced initiation of a Phase I clinical trial of its IMG529 anti-cancer compound for non-Hodgkin's lymphoma patients. The drug contains a B-cell targeting antibody, CD37, attached to a potent cell-killing agent called DM1. The trial is expected to enroll approximately 55 patients.

P13K Inhibitor Begins Phase III Study – Gilead Sciences, Inc. has begun dosing its first patient in a Phase III study evaluating the efficacy and safety of GS-1101, formerly known as CAL-101. This is an inhibitor of the P13K pathway and is being evaluated in combination with rituximab in previously treated chronic lymphocytic leukemia patients. The trial will enroll 160 patients at approximately 70 sites in the United States and Europe. Phase III studies of GS-1101 in combination with bendamustine and rituximab and in combination with ofatumumab are anticipated to begin enrolling patients later this year. GS-1101 is also in a Phase II study as a potential treatment for indolent non-Hodgkin's lymphoma.

GA101 Antibody Evaluated in Canadian and French Clinical Trials – A Phase I study of obinutuzumab (GA101) from the University of British Columbia in Canada evaluated its safety, tolerability, and activity in patients with relapsed CD20 positive B-cell malignancies. Obinutuzumab is an engineered monoclonal antibody and was administered as induction therapy followed by two years of maintenance. No dose-limiting or unexpected adverse events were observed, although infusion-related reactions were most common, followed by infection, fever, neutropenia, headache, and nausea. At the end of induction therapy, 23% of patients achieved a partial response and 54% had stable disease. Of the patients who received maintenance, the best overall response was 32%. A multi-center study from France also focused on obinutuzumab. In a Phase I study of 21 patients with heavily pretreated, relapsed, or refractory indolent non-Hodgkin's lymphoma, the best overall response was 43%. Again, infusion-related reactions were the most common adverse events in this trial.

Mozobil Use for Stem Cell Collection Approved in Canada – Sanofi Canada announced that Mozobil, a new treatment for the mobilization of stem cells in patients with non-Hodgkin's lymphoma and multiple myeloma, is now available on the Canadian market. Mozobil is intended to be used in combination with granulocyte-colony stimulating factor (G-CSF) for the collection of stem cells in order to be able to perform an autologous transplant.

FDA Approves Investigational New Anti-CD20 Antibody for Clinical Trials – The U.S. Food and Drug Administration has cleared an investigational new drug application for TGTX-1101, also known as ublituximab, a novel third generation chimeric monoclonal antibody targeting a unique part of the CD20 antigen found on B-cells. TG Therapeutics, Inc. is now permitted to begin a Phase I/II clinical trial in patients with B-cell lymphomas, which the company plans to do this year. The study will enroll up to 36 patients in the Phase I dose escalation study and up to 77 patients in Phase II. All enrolled patients will be relapsed or refractory to rituximab or to a rituximab-containing regimen.



Trial for Anti-CD19 Antibody Enrolls Patients – MorphoSys AG and Zencor, Inc. announced successful completion of patient enrollment in a Phase I trial evaluating MOR208, an anti-CD19 antibody being developed to treat B-cell malignancies. A total of 30 patients with relapsed or refractory chronic lymphocytic leukemia are enrolled, with results expected to be available later this year. MorphoSys AG plans to initiate additional clinical trials for MOR208 in non-Hodgkin's lymphoma.

Kyprolis (Carfilzomib) Approved for Relapsed/Refractory Multiple Myeloma – Based upon results from a Phase II trial, the U.S. Food and Drug Administration has approved Kyprolis (carfilzomib) for the treatment of multiple myeloma patients meeting specific criteria. The patients must have received at least two prior therapies, including bortezomib (Velcade) and an immunomodulatory agent (lenalidomide, thalidomide, or pomalidomide). The patients must also have demonstrated disease progression on or within 60 days of completing their last therapy.

The study enrolled 266 relapsed and refractory multiple myeloma patients who had received a median of five prior therapies. Overall, 23% responded to Kyprolis, and median duration of response was 7.8 months.

Drug Reduces Graft vs. Host Disease in Allogeneic Transplantation – Allogeneic stem cell transplant patients who are at high risk for graft vs. host disease (GVHD) appear to benefit when maraviroc (Selzentry), a drug used in HIV treatment, is added to the prophylactic regimen. GVHD occurs when the newly-transplanted immune cells perceive the recipient's tissues as foreign and attack them. This finding from the University of Pennsylvania reported that historically GVHD occurs in 30-50% of patients receiving matched transplants from a related donor and in 50-70% of those receiving transplants from an unrelated donor. In this study of 38 transplant patients receiving maraviroc, at day 100 the incidence of grade 2-4 GVHD was 14.7% and for the two higher grades was 2.9%. Maraviroc treatment did not appear to alter the relapse rate of the underlying disease or risk of infection, and it did not slow the amount of time it took for patients' new immune systems to engraft.

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

RYAN SCOFIELD LIVES STRONG WITH WM AND 'IS THE CURE': A TALE OF A MAN, A MARATHON, AND A LOCAL SUPPORT GROUP

BY DON BROWN AND RYAN SCOFIELD

As the support group leader of the Chicago area, Don Brown fields many calls from newly diagnosed WM patients. Some calls are more memorable than others. Here Don recalls an unforgettable call from a young father recently diagnosed with a rare and incurable disease. Don then continues with the story of how Ryan Scofield courageously rose to the challenge of WM, and then Ryan takes over to report on his success as a fundraiser for the IWMMF.

Don leads off:

Several years ago I received a call from a young man, only 35 years old, who had just been diagnosed with Waldenstrom's. Ryan was married, the father of a one year old baby, and in need of treatment. The shocking news that he had an incurable cancer quickly led this young father to anticipate the worst, as many of us have before him. Ryan Scofield, his wife Krista, and baby Arthur visited our home, and we discussed how this disease can be managed with drugs and a good lifestyle and how the IWMMF helps us understand this elusive enemy. Ryan became involved in the Chicago area support group by attending meetings and volunteering to take over management of the mailing list.



Ryan Scofield: ready to run!

In the spring of 2011 I received a thank-you card from Ryan with a picture of him on a mountaintop, little Arthur on his back. The same card had a chart showing his IgM and hemoglobin returning to normal. But that was hardly the end

Ryan Scofield Lives Strong, cont. on page 17





The Ryan Scofield Team after the marathon: l. to r., Denise Voelker, Krista McKim, Ryan Scofield, Arthur Scofield, Chris Souther. The Team raised \$7,000 by “fundraising with their feet.”

of this heart-warming tale! Once Ryan had his WM under control, he proceeded to organize a local fundraising effort for WM by running in the Chicago Allstate Half Marathon on June 9 with his good friends, Chris and Denise. He set up a special website for donations, asked a friend to design a logo,

and had T-Shirts made – all leading to generous gifts totaling over \$7,000 for the IWMF Research Fund, thanks to his many friends and support group members who participated in the special event by sending contributions. My wife Mary and I were so thankful to be able to watch Ryan and his two friends run for a cure. We hope that many of you will do the same, whether organizing a special event or just writing a check to either our Member Services Fund or our Research Fund. (And see page 24 for a photo of Mary and Don Brown modeling the Ryan Scofield T-shirt!)

Ryan chimes in:

By the time I had my WM under control, it became clear to me that many people want to come together to help others in times of need. It was remarkable, and it is likely that many WMers have also felt that love. When my treatments were complete, I wanted to put myself on the giving end of that relationship and be a part of the cure. I had no experience in fundraising but figured I could do the run for my own health and raise some money in the process.

Ryan Scofield Lives Strong, cont. on page 33

COOKS' HAPPY HOUR

BY PENNI WISNER

How to Take a Nap: Inspired by Peter DeNardis

In the past when we lived closer to our agrarian roots, many tradition-minded families would butcher a fat pig and cure their own meats. Now that all things porcine have captured the attention of DIYs and food enthusiasts, this harvest ritual is being rediscovered. An early adopter is IWMF Trustee, Peter DeNardis, who makes his own prosciutto.

Fear not, you will not find a prosciutto recipe here. But if you did...it might begin: “Start four years before you plan to serve your prosciutto. First, buy yourself some property that includes acres of mixed forest rangeland. Then buy a piglet, preferably an Italian heritage breed such as the Cinta Senese. Let it forage on acorns, herbs, and mushrooms for two years. This should give you time to find someone to slaughter and butcher your pig.” You get the idea. Contemplating that, plus the months of aging a prosciutto requires, yields a greater understanding of why high-quality prosciutto costs what it does. It might also partially explain why we eat it sliced so thinly. Its intensity of flavor provides most of the rationale.

We asked Peter to give us some Cooks' Happy Hour ideas for prosciutto. Here is his response: “You know, mostly I eat my prosciutto ‘straight up’ with a hunk of good, hard Italian bread. Or at most, I wrap a slice of prosciutto around a slice of cantaloupe.

“As for appetizers or hors d’oeuvres, I usually do something like an appetizer tray made up of some sliced fontina,

parmigiano reggiano, asiago, pepper jack, and provolone cheeses; slices of dried sausage, prosciutto, sopressata, and capicola; and then some good, green Italian or Greek olives; strips of roasted red peppers; and good bread. It goes so well with sitting around drinking wine (lots of resveratrol, of course). You are set for a wonderful time of nibbling, drinking, and sharing stories through a long afternoon followed by a wine-induced nap afterwards.”

His comments remind me that now – as the days shorten and the late afternoons get a bit chilly – is a great time to take ourselves outdoors to soak up those last rays of sunlight while they still carry some warmth. And to do that with food means, to me, to cook with foods bursting with intense color and goodness given by all that summer sunshine and heat. I.e. peppers, corn, and eggplant, to name just three. And we’ll sweeten them with roasted and smoky flavors because now, too, is the time for warming fires. Naturally, they all taste better with a side of prosciutto.

One of the very simplest hors d’oeuvres is to open a jar piquillo peppers from Spain. As good as homemade roasted sweet red bell peppers are, especially when you use ripe peppers from the farmers market, piquillo roasted peppers from Spain have an extra level of savor, a unique perfume that makes them worth seeking out. Drain the peppers, saving the juices for a vinaigrette, and arrange them in a dish. Pour over

Cooks' Happy Hour, cont. on page 18



good olive oil – it must be fresh and very good – and sprinkle with thinly sliced, toasted garlic plus salt and pepper. Serve with crusty bread.

Now you can make yourself pretty little bites of corn salad served in small leaves of little gem lettuces: Microwave the corn, still in its husks, for several minutes. (This makes the silk slip off easily when you husk the corn.) Return the corn to the microwave for another few minutes if it needs it. Then cut the kernels off the cob and put them in a bowl. Add minced serrano chile, roughly chopped cilantro, halved cherry tomatoes, and some red onion, diced very small and left to soak in lime juice for several minutes. Make a vinaigrette with more fresh lime juice, olive oil, salt and pepper. Hmmm, now, bacon has a nice smoky flavor. How about dicing some of that and adding it to your salad?

Eggplants come on strong in the fall and they are among my favorite foods simply sliced, brushed with olive oil, and grilled until meltingly tender. You could make a real grilled cheese sandwich by grilling the bread, topping it with slices of mozzarella to melt in the grill's heat, perhaps some roasted peppers, and then your grilled eggplant. Just try to beat that for flavor. Oh, okay, go ahead and up the ante by seasoning with smoked salt or Spanish smoked paprika.

In the oven when it rains, on the grill when it's nice, or in the fireplace when it's cold, roast eggplants whole, turning them until they are cooked and tender throughout. The flesh takes on a wonderful smoky flavor. Scoop the flesh out of the skin and drain it. Then spoon it into a food processor with tahini, garlic, lemon juice, pinch of toasted cumin, salt, pepper, and olive oil. Now you have baba ghanoush to serve with bread, crackers, or a spoon. Or take that roasted eggplant and brrr it up in your processor with peeled and seeded tomatoes (roasting them is your choice), onion, garlic, cilantro or parsley, lemon juice, olive oil, and salt and pepper.

Every fall, I talk about tomatoes so I will again. Just to be consistent. Perhaps you've made or purchased some sun-dried tomatoes. Process them with pitted kalamata olives, shallots, garlic, maybe some fresh thyme or oregano, salt, pepper, Spanish paprika, and, of course, olive oil. Transfer your mixture to a bowl ringed with croutons, douse the tomato tapenade with a little more olive oil, pour yourself a glass of wine (lately I've become very fond of grenache/garnacha), and go watch that sunset.

Our motto: Eat well to live well.

DOUBLE ACCOLADES FOR PETER DeNARDIS



April 19, 2012: Jefferson Awardee Peter DeNardis (far right) and his wife Terri (third from right) were fêted in Carnegie Hall.

Our own Peter DeNardis has recently been honored for outstanding public service – not once but twice. In the October *Torch* of 2011 (issue 12.4, pages 4 and 13) we reported that, sponsored by the *Pittsburgh Post-Gazette*, Peter was a recipient of the prestigious Jefferson Award, which since 1972 honors outstanding community and public service in America. Peter was among fifty “community champions” in the Western Pennsylvania area. Peter’s award was primarily for his service to the IWMF. The formal award ceremony took place on April 19 in Pittsburgh’s Carnegie Hall, when Peter was presented with a splendid medallion created by the Franklin Mint for Jefferson Award recipients.

More recently Pete’s service to the public was lauded by the University of Pittsburgh where Peter is employed as an Information Manager.

Of the University’s 7,000 full-time employees, Peter was one of two honored on June 26 as recipients of the 2012 University of Pittsburgh Chancellor’s Award for Staff for Excellence in Service to the Community.

Among the communities for which Peter contributes so much of his time, energy, and talents is the WM community represented by our Foundation. Every member of the IWMF benefits from Peter’s service! He sits on the IWMF Board of Trustees, he manages IWMF-Talk, he administers our website *iwmf.com*, and he is currently a key member of the team forging ahead to complete the Patient Database.

In his spare time Peter the oenophile makes his own fine wines. Let’s now raise a glass to Peter to congratulate him for his two-fold recognition and to express gratitude for his outstanding volunteer commitment to the IWMF!



The Jefferson medallion awarded to Peter on April 19.



INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

MEETING OF EUROPEAN WM NETWORK'S AFFILIATES LONDON, MARCH 10, 2012

No fewer than ten countries were represented at the meeting of EWMnetwork's affiliates that took place at The Royal Society of Medicine in advance of the Third International Patient Forum, organized by WMUK, that took place the following day. The meeting also benefited from the presence of Dr. Guy Sherwood, a Trustee of IWMF. Fruitful discussion of a number of issues of crucial importance to WM patients and carers was facilitated by the able chairmanship of Lia van Ginneken, President.

Although EWMnetwork is an umbrella organization whose membership is mainly made up of WM patient support groups, individuals can join if their country does not have such a group. The value of such a membership policy was underlined by the fact that several attending the meeting came from countries without dedicated WM support organizations who were thus able to describe personally to the meeting the precise challenges they face in making contact with fellow patients or in obtaining access to current information on WM and its treatment. Such personal insights gave added impetus to EWMnetwork's desire to see more patient groups established, and a large part of the meeting was devoted to discussion of how to stimulate the foundation of groups and give them access to information in their own languages.

Those attending were given a clear understanding of how EWMnetwork fits into a wider network of umbrella organizations established within Europe in order to lobby more effectively for those affected by WM. At the same time the meeting recognized the gap between needs and resources in the case of a disease that is at once rare and at the same time predominantly affects older people. Against this background it was particularly valuable that the meeting recognized the crucial role played by the IWMF in disseminating the most accurate and authoritative information and in funding research. One challenge that lies ahead is to develop organizations and structures that fit the European context, with its variety of languages and cultures, while at the same time playing the fullest possible part in the worldwide battle against a puzzling and uncommon disease.

Phil Manning, WMUK, reporting

THIRD INTERNATIONAL PATIENT FORUM: LONDON 2012

The Third International Patient Forum at the Royal Society of Medicine in March attracted 225 patients, doctors, and caregivers from 14 countries from as far as Hong Kong, with keynote speaker Dr. Steven Treon giving us his latest research

on WM genetics. WMUK hosted and organized the meeting, which was generously supported by the IWMF and European WM network. We also hosted an exceptionally well-attended EWMn associates meeting the day before as well as a 'thank you' dinner in the evening where contributors to progress in treatment and care in WM were presented with unique glass plaques. See above for the report by Phil Manning on the EWMn meeting.

WMUK is a charitable partnership between doctors and patients, and the Forum strap line was 'bringing doctors and patients closer in London 2012.' Apart from the lineup of world experts in WM giving us their latest findings, there were two successful innovations to cement these links. The first was 'Meet the Doctor Lite' where a panel of doctors and nurses individually met patients and carers during session breaks – a 'Speed Dating' session which was much appreciated, and the 'Patient Wall' with panels featuring 25 UK and European patients who laid bare their WM history. This candid display moved not only the newly diagnosed but also the doctors, who may not see the whole picture of treatment and its impact on families.

Partner organizations such as the Lymphoma Association, The Binding Site, Macmillan Cancer, Rare Disease UK, and the National Cancer Research Network offered advice from displays in the atrium with the most visited being the IWMF stall ably manned by Sara McKinnie. We were also privileged to have artist Karen Lee Sobol from Boston of *Twelve Weeks* book fame who spoke of her clinical trial at Dana-Farber.

The speaker program included European speakers Dr. Eva Kimby, Dr. Pierre Morel, Dr. Pierre Wijermans, and the UK team of seven led by Dr. Shirley D'Sa. Dr. Guy Sherwood outlined the role of the IWMF and Lia Van Ginneken–Noordman the EWMnetwork. The day concluded with the ever-popular 'Meet the Doctor' session, interactive voting allowing the audience the chance to choose the questions put to the panel. As usual we ran out of time and all went away exhausted with plenty to think about. Further details of the program are available at www.wmuk.org.uk

Next year's WMUK meeting is scheduled for Sunday 17 March 2013 at the new Royal College of General Practitioners HQ at Euston, London, and the EWMn will also hold its European associates' meeting there, so there will again be a distinct international dimension. It is likely that both the UK and Dutch Treatment Guidelines will be also launched at the meeting. It is possible that this large venue will be a dry run for the International Workshop, due to be held in London 2014. To be kept updated on our 2013 meeting just send an e-mail to info@wmuk.org.uk To keep costs low we created in house a DVD of all presentations. It has sold very well,

International Scene, cont. on page 20



now in its second edition, and is still available for £12/\$16 including postage.

Roger Brown, WMUK, reporting

AUSTRALIAN SUPPORT GROUP

The WMozzies support group has focused on patient support and advocacy, as opposed to discussion of the latest promises of hematology research. In Australian healthcare, both the formal regulatory and medical professional environments are conservatively insensitive to the needs of patients with rare diseases such as Waldenstrom. Innovation is tardy, especially for those who face first treatment. Wider options are available for relapsed or refractory disease, but even so, the small population base limits drug access and caregiver interest. Likely enough, we will deliver most practical benefit to WM patients in Australia by identifying our common human needs alongside persons with other indolent lymphomas or rare tumors. One such point of visibility has been developed by Andrew Warden through collaborative effort with the CART-WHEEL Center for Analysis of Rare Tumors.

As always, patient and caregiver proactivity is essential for achieving the best prospects, but in reality outcomes are sensitive to an individual's circumstances regarding privately funded versus public health care and hospitalization. It appears that the only way to alleviate the formally embedded lethargy is through well-chosen advocacy initiatives. Without advocacy, something terrible happens – nothing.

Our support group leadership team is active at several fronts in this regard. We are now having regular discussion forums and luncheons for patients and caregivers, taking advantage of organizational assistance and support from the Leukaemia Foundation of Queensland (LFQ) – for meetings in Brisbane – and the Leukaemia Foundation of Australia (LFA) – for those in Sydney. Next on the list of venues must be Melbourne. Without access to the experience of more adventurous or fortunate patients, uncertainty remains. Information becomes available only by thoughtful sharing between us all. My thanks for the ongoing willingness of our members to assist where they are able!

Colin Perrott, WMozzies reporting

WALDENSTRÖM FRANCE ASSOCIATION

The Waldenström France Association will hold its fifth meeting in Vienna, France, on September, 29, 2012, with participation of Professor Pierre Morel from Lens, France. During that day patients will be able to participate in the famous “Ask the Doctor” session and in the general assembly of the association. We hope to have more than thirty persons from all over France attending – there are 110 members in the French association.

Michel Houche, Waldenström France Association, reporting

FROM IWMF-TALK

BY MITCH ORFUSS

As a daily reader of IWMF-Talk in order to prepare this column, I take note of how the content is evolving. In 2012, there was a significant increase in the number of IWMF-Talk discussions about treatments, both standard and new. It appears that we who use IWMF-Talk are increasingly asking others about treatment – perhaps because we are fortunate to have so many more options (present and emerging from trials) than there were just a few short years ago. It makes the year 2000, just to pick a nice round number, seem almost like the Middle Ages in terms of understanding and combating our orphan condition. It's never a good time to get a cancer diagnosis, but, generally speaking, there have never been so many powerful, yet low-toxic, weapons in the oncological arsenal to help us square off against Waldenstrom's as we have available or quickly emerging today. The sharp increase in effective treatment options and the differing ways they go about killing tumors clearly excite IWMF-Talk readers and make us more curious to better, and more thoroughly, understand these treatments so we can make good decisions in concert with our doctors and families. The IWMF-Talk summary that follows is, of course, not limited to treatments

but indicates our readers' expanding interest in the new medicines that are coming our way in the short term. WM patients never stop amazing me as an exceptionally intelligent and inquisitive group!

Bendamustine

“Benda” was the most frequent IWMF-Talk discussion topic over the first half of 2012, and why wouldn't it be when Dr. Treon refers to it (in combination with Rituxan) as a candidate to be considered the new standard of care for WM? **Anita Lawson** wrote that she had five rounds of bendamustine and Rituxan after developing a persistent sinus infection (from low IgG) and was not well enough for the sixth infusion. Premeds with Rituxan included Zofran, Pepcid, Tylenol, Decadron, and Benadryl. Side effects, other than persistent fatigue, were primarily gastro-intestinal: nausea, some anorexia, constipation. Unpleasant, but tolerable, considering the results. Anita had the most notable improvements after rounds one and two, with IgM halved each time: 3100+ to 1570 and then again to 757. The last 3 rounds produced smaller decreases to a current low of 316. Once Anita finally

From IWMF-Talk, cont. on page 21



recovered from the sinus infection (which took 6 months), she said she started to feel human again. Considering the excellent results, she would put up with the side effects again.

Kenneth Leung also told his bendamustine story: he had started 6 cycles of bendamustine plus Rituxan with 4 weeks in each cycle. This time, he tolerated it well. In the first 2 rounds, nausea was minimal. Appetite was unaffected and there was no weight loss or other discomfort. Kenneth was pleased to mention he could still manage to golf every other day. However, his feet often got numb, which his doctor said was a typical side effect. After the fifth cycle Ken's IgM decreased to 1,350 from 2,010, and the paraprotein reduced to 9.6 from 17. His doctor and he were happy with this progress. Ken was concerned that his hemoglobin, white count, neutrophils and platelets all decreased after each cycle. Before each cycle he therefore took a shot of Epogen to counter these effects. In spite of the suppression, Ken continued to feel energetic.

Tony R. Brown added his experience: after the fourth round of single-agent bendamustine, his IgM went down from 3930 to 509, M-spike down from 1.96 to 0.27, hemoglobin up from 10.7 to 12.9, WBC counts down from 6.7 to 3.2. He took Neulasta on the third day after each two-day series of bendamustine to boost WBC counts. Tony wrote that his "doctor decided it best to wait 4 weeks instead of the normal three weeks between treatments of bendamustine to allow the WBC counts to get at least back near the low end of the normal range before the next treatment." Tony called his results "amazing" relative to his prior 6 rounds of R-CVP at 50% dose in 2007 and eight rounds of CVP at 75% dose in 2010. He says his system cannot tolerate Rituxan. Tony experienced major nausea with the first round of bendamustine for four weeks. Other side effects were chills, flushed (red) face, feeling tired and achy during the first week after each treatment – and then back to normal the third week. He takes two acetaminophen to counter the tired and achy feeling. Bottom line: Tony's cancer load as measured by IgM and M-spike is currently lower than any time since he was diagnosed with WM. He ended with a prudent word of caution: "what works well for one of us may not work well for others." There were many more posts about bendamustine.

Coughing

Coughing was also a hot topic on IWMF-Talk. Diagnosed in 1998, **Abbas Mirrashidi** wrote that, while on Rituxan

maintenance, he started coughing so severely that he took six days of antibiotic, which did not help. **Dr. Guy Sherwood** suggested it was time for a chest x-ray. **Gini Marshall** said she too had a horrible cough all winter, diagnosed as the result of everything from sinus infection to asthma. It resolved after Gini's first round of IVIg but then came back, if not as severe. Gini was told that the IgG level directly relates to respiratory immunity, so it sounds logical that, since most of us have low IgG, we would tend to have respiratory issues.

Gerald Wergland added that, when he was diagnosed, one of Dr. Treon's warnings was to take an antibiotic such as Levaquin at the onset of sinus and other respiratory ailments rather than waiting, as someone with a normal immune response might. As he is allergic to Levaquin, Gerry takes Augmentin (amoxicillin) instead. That, coupled with Flonase nasal spray, quickly knocks out sinusitis and cough. Gerry sometimes has trouble convincing local doctors to write the prescription for Augmentin at the onset of respiratory problems as many doctors try not to overmedicate with antibiotics. The WM community, and others with compromised immune systems, might base their decision on a different set of rules. Gerry is pleased to be cough-free for almost six months, no longer living on a steady diet of Hall's cough drops!

Dr. Tom Hoffman responded that he would have to agree with **Dr. Guy Sherwood** that most of Gerry's infections were probably viral. Tom appreciated what Doctor Treon told Gerry but said that an infectious-disease doctor would tell you that it is not the best approach to begin antibiotics at the onset of respiratory problems. The problem with taking broad spectrum antibiotics repeatedly is that the antibiotics will kill off all the bugs it works against, with the result that you may possibly develop a "superbug" infection which responds to nothing. This is the main reason that we have superbugs and that antibiotics are not as effective as they once were.

Fionna in Scotland agreed with Tom and Guy but with some reservations. Until last year, the cough that seems to be ubiquitous with WM accompanied her for most of the twelve years since her diagnosis in 1999. Fionna travels a lot, sometimes far from medical help, so was advised to carry antibiotics (along with a week's worth of Acyclovir to deal with a potential outbreak of shingles). "On one occasion," notes Fionna, "I ignored a gum boil which I found mildly

From IWMF-Talk, cont. on page 22

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



uncomfortable but didn't take seriously...until too late! If I had taken my antibiotics, I could have avoided the subsequent week in the hospital." Fionna accepted the cough as part of having WM – until she was treated with R-CHOP and IVIg one winter. She has not coughed since and realizes now how much better she is. Used sensibly, antibiotics can be a good addition to one's arsenal.

Julie Kansa wrote that she had a persistent dry but occasionally productive cough since the first day of cycle 5 of her bendamustine-Rituxan protocol. At the end of the day she experienced tightening in the chest and was treated with Benadryl. Later that evening the cough started and has been with her since. Julie was tested for the flu and other viruses several times and each time results were negative. Chest x-rays also negative. She did not run a temperature but did not feel well since cycle 5. Julie's oncologist decided that the risk of receiving cycle 6 exceeded the benefit and so gave her a break for 8-10 weeks. Otherwise, she responded to treatment. IgM, viscosity, M-spike and so on continued to improve. Out of the blue, she spiked a 102 temp and started on Augmentin only to feel worse, not better. In addition she started experiencing pain around the line in her neck that is part of a power port. She ended up in a hospital bed receiving IV antibiotics and codeine cough medicine while the problem was investigated. Her gut feeling was that she had an extended reaction to the bendamustine-Rituxan combination.

Marilyn Bagel responded that she too had a persistent cough after four monthly treatments of bendamustine-Rituxan. Her chest X-ray was clear, the cough was not constant but more like that from an allergy. And when she lay down, it went away. Marilyn began a maintenance regimen of Rituxan every other month. Her bone marrow biopsy, which initially showed 70% cell involvement, went to zero after this treatment. She called it "a miracle." Marilyn felt she could tolerate the cough, annoying as it was. Marilyn has not taken prescription meds for this as she avoids taking additional meds unless absolutely necessary.

Reduced Velcade Dosing

When a IWMF-Talk reader asked about Velcade dosing, **Hank Stupi** said he didn't recall any formal studies or trials using a reduced dosage. Most of what Hank remembered is anecdotal. For the last couple of years Hank was taking Velcade intravenously at 1.0 mg/m² (down from 1.6 mg/m²) once a week for three weeks followed by a week off. He switched to subcutaneous injections (now FDA approved as a means of administration) within the last year. Velcade administered subcutaneously is thought to be just as effective as by IV-push but with less peripheral neuropathy resulting. **Gini Marshall** said she too was on weekly Velcade injections but not with week three off. She asked if anyone finds it beneficial to skip the third week and, if so, why? Gini added that her neuropathy was stable since the injections.

David Bingham then reminded us that Velcade is both a medicine (makes you better) and a poison (does bad things). The good side is that it can kill cancer cells, the bad is that 30% of us can develop serious neuropathy. For David, Velcade lowered his WBC and platelets almost to zero, requiring platelet infusions. David started out at doses that were apparently too high or too frequent. Reducing injections to once a week and then missing a couple of weeks resulted in David's finding a schedule that kept his platelets and white cell count at low, but acceptable, values and his red cells at a low, but not dangerously low, level. So each of us, he suggests, must find his or her own schedule through experimentation. David still skis, and he walks a couple of miles each day, managing his disease so that it barely compromises his quality of life. David considers himself fortunate, finally advising that those on Velcade should probably experiment with their doctors to see if this effective drug can be adjusted to counter negative side effects.

Tony Peterson in the UK mentioned his own very positive results with Velcade. Tony entered a trial at Bart's London (2004-05) for Velcade and Rituxan, and as one of the first participants he only received 60% of the normal dose, once a week for four weeks followed by one week off (for six cycles in all). Tony saw a very gradual reduction in IgM over a couple of years, from 3000 at start of the Velcade and Rituxan treatment, down to 2000, then to 1400 a few years after that, then a leveling off at 1100 for the past two years.

And much more.

In addition, the chat on IWMF-Talk over the past few months touched on many other WM topics of interest. To give you a sense of the scope, they included such relevant concerns as joint pain, serum viscosity, Cytosan and Decadron, benzene, age, slower infusions, Bing-Neel, blocked ears, X-rays, weight loss, lymph nodes, LBH589 (Panobinostat), RAD001 (everolimus), and blood pressure – an assortment that hardly dents the range of inquiry! No matter what you may want to report to IWMF-Talk or hear about related to WM, there are experienced, interested, and generous fellow-WM-travelers who want to listen and offer their points of view on IWMF-Talk. So please join and use the IWMF talklist. Share your particular story. Ask a question. Respond to a fellow sufferer. Participating feels good and brings us closer together. However: please never forget that no one practices medicine on IWMF-Talk. WM patients differ markedly from one to another, and only you and your doctor are sufficiently informed about your individual variant of WM to make treatment decisions.

Until the next *Torch*, wishing best of health to you all!



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 26-27.



At the 2012 Ed Forum in Philadelphia, northern California was well represented: l. to r., Jennifer Hoegerman, Jim Wohltmann, Alyce Rossow, Lee Howard, John Howard, Terry Rossow, Judith May, Tom White, Sharon Ekin, Jack Ekin. (not pictured, Michael Luttrell)

CALIFORNIA

Sacramento and Bay Area

Eleven members attended the IWMF Educational Forum this past spring. Two of them, **Michael Luttrell**, assisted by **Terry Rossow**, recorded the proceedings. (When you buy those nice DVDs from the Forums, these are the men responsible for them.) Saturday noon at the luncheon (see page 4), the group heard that its own **Penni Wisner** had joined the Ben Rude Society. (Ben Rude was the second president of the IWMF; the Society was founded as a way to make a significant financial contribution to research.) Saturday night found the group feasting together and spending the hours getting acquainted. The following month, the group met again in their long-term location at the Vallejo Kaiser Hospital to share with everyone what had been learned at the Forum. **John** and **Lee Howard** presented an excellent account of what it felt like to attend the Forum for the first time. **Alyce** and **Terry Rossow** added other highlights from the meetings and answered the many questions posed by the ten other attendees. After breaking for potluck munchies, individuals shared their progress with Waldenstrom's. A fall meeting was held at the Roseville Kaiser. Meetings alternate between Vallejo and Roseville to try to make it more convenient for attendees from the large area our support group serves.

COLORADO & WYOMING

The Rocky Mountain Blood Cancer Conference, the Leukemia & Lymphoma Society event held on April 14, provided an opportunity for the area's IWMF support group to meet for "Lunch with the Experts" – including our local WM expert doctor, Dr. Jeffrey Matous, of the Colorado Blood Cancer Institute. The members enjoyed an

energetic hour with Dr. Matous in a Q & A format with a free box lunch courtesy of the LLS. Dr. Matous also reviewed Dr. Irene Ghobrial's Tissue Bank Study funded by the IWMF, outlining the requirements and encouraging any of us with upcoming bone marrow biopsies to participate. (See page 3 of this issue) He even handed out the necessary forms. The morning sessions included an excellent keynote speaker, Dr. Tony Shapiro from Penn State, who was hilarious on the perils of cancer treatments. Dr. Lou DeGennaro of the LLS research program reviewed its \$57 million funding of cancer research (some of it jointly funded with the IWMF for WM-specific research). The afternoon allowed for two more sessions on various topics such as nutrition, cancer survivorship, Medicare, and caregiver stress. Twenty-four WM patients and their caregivers attended the conference. While there, a new WMer discovered and joined the group. Plus a good number of nurses attended our session with



Dr. Jeffrey Matous discussing treatment options with Paul Millrad, from Aurora, CO, during the LLS one-day conference.

Dr. Matous. The conference was very informative, and it was great to compare notes with WM patients – all in all a great partnership between the IWMF and LLS. A fall meeting is being planned to review the 2012 Ed Forum DVDs and show "The Garden Updated" by Dr. Morie Gertz.

ILLINOIS

Chicago Area/SE Wisconsin

In spring 2012, more than forty members greeted guest lecturer Dr. Sherine Elsawa from Northern Illinois University where she is an assistant professor doing Waldenstrom's research in our own backyard. Dr. Elsawa has a Ph.D. from the University of North Carolina and completed her postdoctoral work from 2003 to 2011 at the Mayo Clinic. Her comprehensive presentation on WM research and the following Q & A received numerous compliments. June was a special month for the group as well. **Ryan Scofield** ran

Support Group News, cont. on page 24





Mary and Don Brown sport the Ryan Scofield T-shirt designed for the Chicago Allstate Half Marathon on June 9 when Ryan and his team ran for the Cure on behalf of the IWFM.

the Chicago Allstate Half-Marathon with some friends (see page 17). This well organized event demonstrates how IWFM support groups can make a difference! In the photo above, **Don** and **Mary Brown** model the "Be the Cure" T-Shirts designed



A perfect summer day, hearty fare and home brew, sporting events – the Chicago area support group's annual picnic provided a good time for all ages.

by Ryan's friend. The support group's fourth annual picnic in August attracted forty-one participants from southeast Wisconsin and south central Illinois. The event provided a special time of fellowship, sharing stories, and good food. Fresh-raised beef burgers from **Sara** and **Mike Thran** and fresh brats with Don Brown's "world (loosely used) famous" beer (could it be a substitute for Rituxan?!) recipe were on the menu. In honor of the Summer Olympics, ping-pong and bean-bag competitions were held. Watch for details about the fall meeting planned for Saturday, 20 October. The discussion topic will be estate planning featuring the IWFM senior development officer Dave Benson. If time permits, the "Ask the Doctor" 2012 Educational Forum video will be shown.



Dr. Rafat Abonour spoke to the Indiana support group regarding transplant options for WM patients.

INDIANA

In March the Indiana group hosted Dr. Rafat Abonour who discussed stem cell transplants. His detailed presentation sparked much discussion. In June a dietician spoke with the members about diet and appropriate food groups. The next meeting is planned for Saturday 10 November at 10 am.

Support Group News, cont. on page 25

C. EDWIN BAKER TRUST MAKES BEQUEST TO IWFM

The IWFM is pleased to report an unsolicited donation made recently by the C. Edwin Baker Trust, a gift both unexpected and wonderful. According to Nancy Lynn Baker, Trustee of the C. Edwin Baker Trust and sister of Mr. Baker, Edwin Baker was a prolific scholar and professor of law, for much of his career a professor of law at the University of Pennsylvania. He elected to lead a simple life, and at his death in 2009 he left the bulk of his estate to charity, without specifying the recipients. A Charitable Gifts Committee was named to select organizations worthy of support. Because her brother cared deeply about the welfare of his friends, Nancy Baker and the Committee designated the IWFM as a recipient in honor of a close friend of Mr. Baker who was recently diagnosed with WM.

The IWFM is grateful for this bequest and wishes to express thanks to the Committee and especially to Nancy Lynn Baker.



NORTHEAST KANSAS & NORTHWEST MISSOURI

On June 29, 2010 the newly formed support group met for the first time with seventeen members present. The membership has grown rapidly and currently stands at thirty. Another newly diagnosed WMer is expected to join at the August meeting. As proof that WM doesn't have to slow one down, one couple rides their motorcycle down from Lincoln, NE, to the meetings, which are held every other month and usually feature a speaker. Topics have included acupuncture, genetics, neurology, and ophthalmology. Everyone learns from everyone else and enjoys the mutual support.

NEW YORK

New York City

Fifteen members of the New York metro-area group, plus a couple of spouses, showed up on a beautiful July afternoon for a two-hour discussion focused on new treatments and welcomed several new members as well as one returning member. Members feel fortunate that, living in the number-1 metro area, they have easy access to hospitals offering the latest trials, and many in the group are interested in exploring these options. **Mitch Orfuss**, the support group leader, had mentioned two months ago a trial for PCI-32765 that he would be entering. The group seemed eager for an update, which, he reported, was fortunately positive so far. Folks seemed to leave feeling that though it's never a good time to have WM, these are the best of all times to have it, with better news on the horizon.

Eastern NY/Western New England

The "happy warriors" have been busy beavers. Sixteen members enjoyed the food and conversation at the annual spring luncheon. And eight of the group ventured into the "inner sanctum" of Philadelphia in early June for the IWMF Educational Forum. They listened eagerly to the parade of dedicated doctors presenting exciting research results as they delve ever more deeply into the mysteries of WM. There were several very promising new discoveries, drugs, trials, and names and abbreviations to try to remember. The "Ask the Doctor" panel was once again a highlight of the weekend. One key take-away is that research is inching ever nearer to the point where WM, while not yet curable, is close to

becoming a chronic disease and that long-term survival time continues to increase. In June members attended a regular meeting at the ACS Hope Club in Latham to review notes from the Forum, plan the annual summer picnic, and discuss potential speakers for fall programs. The discussion included the importance of clinical trials and the need for donations to IWMF to help with funding research grants. In August the annual picnic took place at the always-welcoming home of **Tom** and **Kay Zolezzi**. Over a dozen members enjoyed their supreme hospitality and beautiful backyard (complete with pool and fountain) and shared lots of delicious potluck contributions.

OREGON/SOUTHWEST WASHINGTON

On a sunny Saturday in July the group met for its usual last-Saturday-of-the-first-month-of-the-new-quarter gathering. After a delightful buffet luncheon, **Joel Rosenblit** welcomed members and opened the general check-in. **Jules Auger** then introduced the speaker, Wendy Talbot, an oncology social worker (also a cancer survivor), who works with Legacy Cancer Services at Legacy Good Samaritan Medical Center in Portland. Her personal and professional experience made her presentation "Coping With A Cancer Diagnosis" extremely effective. The group was very engaged with Wendy as she outlined the emotional aspects of having this disease. She described the initial reactions on hearing the word "cancer" and then described some of the emotions in the subsequent struggle as patients move toward accepting the diagnosis, learning about the disease, and exploring treatment options. She shared some tools for measuring stress reactions and some materials about anxiety and depression, two emotions commonly known to many who take the WM journey. Wendy also shared a helpful outline entitled "Helping Yourself Live When You Are Seriously Ill." The ensuing group discussion was lively and responsive to her questions and leadership. All present expressed their appreciation for the presentation and sharing. The group is a collaborative effort between IWMF and the Leukemia & Lymphoma Society. The LLS provides the meeting place and speakers. The next meeting is planned for Saturday, 27 October, at the Fairfield Inn & Suites, 6100 SW Meadows Road, Lake Oswego, OR, from 12 noon to 2 pm.

RECAPTURE THE BEST OF THE IWMF 2012 EDUCATIONAL FORUM (THE "PHILLY FORUM")

The 2012 Ed Forum Review is online in pdf format and waiting for you at
iwmf.com/docs/EdForumReview2012.pdf

The Ed Forum 2012 DVDs. Place your order at *IWMF.com* under *IWMF Library: Ed Forum DVDs* or complete and return the form at the bottom of page 31. Cost of the full set: \$14



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

ARKANSAS

Eastern

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

CALIFORNIA

Monterey

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

Orange County

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

Sacramento/San Francisco

Bay Area

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

COLORADO

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

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

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

CONNECTICUT

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

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

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

DELAWARE

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

FLORIDA

Ft. Lauderdale Area

Charlie Koch
954-476-8726
bonnie143@bellsouth.net

Phil Lewis
561-307-0100
zentamental@gmail.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

Regional Contact:

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

MARYLAND

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

MASSACHUSETTS

Boston

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

Judy Christensen
781-335-5698

MICHIGAN

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

MINNESOTA

Minneapolis/St. Paul

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

MISSISSIPPI

Bill Paul
901-767-6630
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
970-667-5343
970-227-4686 cell
cindyfurst@gmail.com

NEVADA

Eastern

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

Las Vegas

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

NEW ENGLAND

Boston

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

Judy Christensen
781-335-5698

Western MA, VT & CT

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

NEW MEXICO

Regional Contact:

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

NEW YORK

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

EASTERN OHIO

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

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

WESTERN OHIO

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

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



IWMF SUPPORT GROUP CHAPTER LISTING

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

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

RHODE ISLAND

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

SOUTH CAROLINA

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

TENNESSEE

Central & Western

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

Eastern

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

TEXAS

Dallas

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

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

Houston

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

Western

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

UTAH

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

VIRGINIA

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

WASHINGTON

Northwest (Seattle Area)

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

Southwest (Portland Area)

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

WASHINGTON D.C., NORTHERN VA

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

WISCONSIN

Northwest WI

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

Southeast WI

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

WYOMING

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

Regional Contact:

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

INTERNATIONAL SUPPORT GROUPS AND CONTACTS

AUSTRALIA

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
suemarg3x3@hotmail.com

Ottawa

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

CANADA (cont.)

Toronto

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

Vancouver

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

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

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
+35312822481
sheilathomsonmail@gmail.com

ISRAEL

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

Roger Brown
Patient Representative
+44 1285 650107
info@wmuk.org.uk
www.wmuk.org.uk

Sussex

Mike Dewhirst
mkdewhirst@yahoo.co.uk

Birmingham & West Midlands

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



THE LIFELINE

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

**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

Cindy Furst..... 970-667-5343
cindyfurst@gmail.com 970-227-4686 cell
Leslie Neustadt..... 518-374-8607
lesbn96317@aol.com
Tom Zolezzi..... 518-475-1514
tkzolezzi@yahoo.com

BORTEZOMIB DEXAMETHASONE & RITUXIMAB (BDR)

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

CHLORAMBUCIL

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

CRYOGLOBULINEMIA

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

ENZASTAURIN

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

FLUDARABINE with cyclophosphamide (Cytosan)

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

FLUDARABINE with Rituxan

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

OFATUMUMAB

Rob Clark..... 518-298-2611

ORAL CYTOXAN

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

James Townsend..... 352-376-3664
Allen Weinert..... 360-683-3495
anweinert@gmail.com

SPLENECTOMY

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

STEM CELL TRANSPLANTS

AUTOLOGOUS

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

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

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

ALLOGENEIC

Eileen Sullivan..... 617-625-6957
Ebsullivan27@gmail.com

Melissa Sawyer..... 303-979-1765
sawyerirish@aol.com

THALIDOMIDE

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

VELCADE

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

SPECIALTY TOPICS

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

NEWLY DIAGNOSED

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

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

SOCIAL SECURITY DISABILITY

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

WATCH AND WAIT

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

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

Guy Lithwin..... 843-234-3310
glithwin@sccost.net

YOUNG WM

Bob Bailey..... Cell 770-633-3536
Bbailey@rune2e.com Wife's Cell 770-361-4859
Laurabailey64@gmail.com

John Borchert..... 440-449-1662
gdvibes@sbcglobal.net

INTERNATIONAL

AUSTRALIA

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



THE LIFELINE

BELGIUM

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

EUROPEAN WM NETWORK

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

FINNISH SPEAKER

Veikko Hoikkala +3585500484864
veikko.hoikkala@dnainternet.net

FRENCH SPEAKER

Guy Sherwood 765-282-4377
guysherwood@comcast.net
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 Rideout +44 1278 782108
ken@4rosetree.fs.co.uk

FLUDARABINE AND RITUXIMAB

Mike Dewhirst
dewhirst_6@hotmail.com

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

UK SUPPORT GROUP ONLINE FORUM

Raphael Altman
raltman@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



continue to give so freely of their time, energy, and spirit. I was a member of this group and am extremely proud to have been the spokesperson for these years.

Those of us who are caretakers of the Foundation as the leaders, the movers and shakers, the many volunteers and the loyal staff, know that we are enriching the lives of several thousand current members daily and perhaps tens of thousands more in the future by our efforts. We all work tirelessly with one thought in mind – to make this Foundation stronger, sustainable, and relevant.

On my watch I tried to carry on the spirit of Arnold Smokler and the devotion of Ben Rude. My focus was on growth, the development of liaisons with other organizations, research institutions, and government agencies, and to give our little disease a larger profile in the competitive cancer arena.

We are now known throughout much of the cancer world as the little organization that could – and did.

Before I turned over the reins, I wanted to be sure that we had capable leadership to follow and procedures to carry this Foundation into the future for as long as it takes to find a cure.

Carl Harrington Elected, cont. from page 1

Foods in White Plains, New York. Carl will be scaling back his business to take on the role of IWFMF President.

Throughout his career, Carl has produced dramatic short and long-term results through strategic vision, innovative and effective cross-functional team building, and external development. We look forward to having Carl apply his creativity and leadership to the IWFMF.

Carl holds a Master of Business Administration in Marketing from the Wharton School at the University of Pennsylvania, and a Master of Arts in Teaching from Brown University. He earned his Bachelor of Arts at Hamilton College.

Seventh International Workshop, cont. from page 10

by young and talented researchers under the direction of their wise and patient mentors.

In the next issue of the *Torch* I will begin a comprehensive summary of these multiple lectures, including the groundbreaking research from Dr. Treon's team at the Bing Center for WM, the debates, and the consensus discussions, as well as my own personal perspectives. The comprehensive summary will also be posted at a later date on the IWFMF website.

As a 12+ year WM survivor, I wish to personally thank the workshop organizers: Drs. Kenneth Anderson, Nikhil

And that day has come. With the creativity and strengths of Carl Harrington and all fourteen members of the current Board of Trustees the IWFMF is in very good and capable hands.

It is time for me to move on to the life I envisioned when I retired. To build our dream home in Mexico, to spend more time playing my cello and traveling to exotic lands, and to enjoy what will inevitably be my final years. I will be seeing you at Ed Forums, and as President Emerita I will work part-time to help increase our research funds and to find new partners for the Foundation. I won't be far away!

We have a fantastic organization with devoted and capable leadership, highly supportive members, and brilliant scientific researchers, and, if all our dreams come true, a future that will last and prosper until we have a cure in hand.

Some day Waldenstrom's macroglobulinemia will be another rare disease of the past in medical history – a distant memory.

Stay well,

Judith

For the past two years, Carl has resided in Center City Philadelphia with his wife, Eleanor (Elly) Levie. They have one adult son who lives and works in upstate New York, not far from where Carl was born and raised.

Carl was diagnosed with WM in 2006 and quickly found his way to the IWFMF and a local support group in the greater Philadelphia area. He has served on the IWFMF Board for three years, taking on the position of Vice President for Fundraising and joining the Executive Board in 2011.

You will be hearing more from Carl as he officially takes on his new role November 15, 2012, when outgoing President Judith May assumes the title of President Emerita after fifteen years on the Board.

Munshi, and Steven Treon of the Dana-Farber Cancer Institute, Boston, MA. Many thanks to the sponsors of the event: Celgene, Cephalon, Millennium, Onyx, IWFMF, and the Peter and Helen Bing Fund for WM. Finally, a special thank you to the Workshop Secretariat, Christopher Patterson of the Dana-Farber Cancer Institute, for coordinating another outstanding event!

The next International Workshop on Waldenström's Macroglobulinemia (IWWM8) will be held in London, England, in 2014. We can be assured that the IWFMF will once again be supporting this premier scientific conference.



blood and marrow and express mail it (in the package you arranged to have sent) back to Dana-Farber Cancer Institute. The only complication is that you must remember to take the initiative and inform Dana-Farber in advance.

The IWMF Tissue Bank Study aims to create a large data sample from a small population. How are we doing so far? To date, a number of patients who visit DFCI have participated. In addition, many attendees at the IWMF Ed Forum signed up. So far, so good. But we need more participation. We can do it! Let's stack the cards in our favor!

At the recent IWMF Ed Forum, I had the opportunity to have a one-on-one breakfast with Dr. Robert Kyle, perhaps the most knowledgeable physician in WM circles. I asked for his opinion about Dr. Ghobrial's IWMF Tissue Bank Study. Dr. Kyle replied that it was a great idea. He said it would be very helpful but – adding this note of warning – he expected

it would be very difficult to get our very busy physicians around the country to actively participate by seeking out patients to enroll.

So here is our challenge. Dr. Irene's Tissue Bank Study needs our data. It is up to you, up to all of us, to be sure this is done. Let us be proactive about good research! To continue to make great progress and to achieve the goals of this observational trial, I urge all readers to take my message seriously and participate now.

PS: If you don't have access to a personal computer and the Internet or if you have any difficulty accessing the questionnaire and consent forms on your computer, you can simply call Dr. Ghobrial's Tissue Bank Study at Dana-Farber Cancer Institute, telephone 617-632-4218. For further information you can reach Jack at 978-273-2449.

13 New Members Join Ben Rude, cont. from page 4

energy! Guy has also designated the IWMF as a recipient of his life insurance policy.

Finally, our last two inductees are our very own IWMF President, **Judith May**, and her husband and former Board member, **Michael Luttrell**. Judith has served on the Board of Trustees since it was formed in 1998 and has been the President of IWMF for the past eight very busy years following Ben's tenure. She was diagnosed in 1997. Michael, also diagnosed in 1997, served on the IWMF Board for three years. Both Judith and Michael have designated the IWMF as a beneficiary in their wills.

Every one of us is the real beneficiary of the generosity these extraordinarily giving people have shown – in the most real way possible. As you think about the roster of Ben Rude members, you should know that this group truly reflects a cross-section of our membership. They are no different from you and me. Most have family, few are what you would call wealthy, but all have set a priority to provide a portion of their estate for the Foundation's future and for all of us. They have made these provisions assuming that there will continue

to be a need for support for the newly diagnosed and their families and additional research needed to identify improved treatments and find a cure for our disease.

If any of you are thinking about your personal estate planning and can find a way to designate even a portion of your resources to enable the IWMF to continue serving members and supporting research, please contact Dave Benson, IWMF's Senior Development Officer, at 952-837-9980; dave@dbenson.com or the IWMF Business Office at 941-927-4963; office@iwmf.com

Please remember how important you are to the IWMF as we are such a small family of rare cancer patients. The IWMF is you! We have an ambitious agenda for education and research. You can make a difference to yourself, your friends, the IWMF, and the world.

Let's thank all the new members for their generous gifts and the support they have shown for the Ben Rude Heritage Society! The best way to thank them is to join them. Let us hear from you today.

ORDER FORM for DVDs of the 2012 EDUCATIONAL FORUM – PHILADELPHIA, PA

Price is \$14, including postage

(Return this form in the enclosed envelope or FAX to 941-927-4467)

I would like to order _____ complete set(s) of DVDs

Name and Address (Please Print) _____

Check Attached ☐ Credit Card Payment ☐ VISA ☐ MasterCard ☐ American Express ☐ Amount\$ _____

Card No.

Expiration Date

Signature of Cardholder _____

Date _____



I appreciated the Forum's balance of lighter moments as the Foundation's unofficial "mayors" of Philadelphia offered their creative multimedia presentation about our host city. And Charlie Lustman was both entertaining and inspiring.

Kudos to the Foundation's Board Members and chairs who went out of their way to be welcoming and include us at their

tables when we broke for meals. You really know how to make a newbie feel at home – another example of my comforter at work.

Oh, and, one more observation: After seeing Dr. Morie Gertz make his presentations, I also learned that, in addition to his being obviously highly knowledgeable, he would be a heckuva lot of fun to go out drinking with.

Presenting Emil Parente, cont. from page 11

three-liter exchange required 4-4 ½ hours. Now Emil has a five-liter exchange requiring about 2 ½-3 hours. Emil has been able to use his veins (instead of a port) for all his PP treatments, although he admits that finding a good nurse for the "stick" is very important to the process.

Emil "discovered" Arnie Smokler and the IWWMF in the mid 1990s and became an IWWMF support group leader for Orange County, California, in 2006. His first support group meeting was at his house with about 15-16 people in attendance. Today, his group uses the auditorium at a local hospital and has about 135-140 members. While Emil has now turned over the job of leader to IWWMF Trustee Marty Glassman, he still remains available to talk to newly diagnosed WM patients. His major advice to these patients is to go to a comprehensive cancer center, at least for backup opinions,

and not to rely solely on a local oncologist who may not have much experience with WM. He also advises that "knowledge is power" and urges new patients to become informed about their disease and to be an active participant with their doctors in the decision making process. To that end, he encourages them to join the IWWMF.

Emil has enjoyed life with his wife, Phyllis, his children, Vicky and Stephen, and now his three grandchildren, Kira, Gianna, and Owen. His philosophy to live as normally as possible has served him well. At 82 years of age, Emil has traveled the world, he has reached a major milestone to see his children grown and with families of their own, and he remains committed to his goal of helping other WMers understand that they too have the potential to achieve and maintain a good quality of life.

Psychological and Social Needs, cont. from page 12

cancer patient's ability to fully participate in their treatment plan. Depression can make people give up the effort to fight their cancer, or their anxiety and fear may be so debilitating that they cannot make decisions regarding their care. Many treatments can impact mood and energy levels, and patients already experiencing depressive symptoms will be further negatively affected by those treatments.

The psychological needs of cancer patients outlined above are real and far from uncommon. Yet at many cancer centers, where "hands on" professionals are more comfortable with and better trained in the medical model of care, screening for emotional distress may be an afterthought. Statistics reveal that approximately "one in three people in oncology clinics show signs of being highly distressed but surprisingly less than one in ten receives a referral for help."²

Addressing the Sociological Needs of the Cancer Patient

The sociological issues occurring within the framework of cancer are numerous. Virtually all areas of our life will feel its oppressive weight. Cancer impacts the relationships and support systems we have cultivated over the years, the domestic life and home management we have maintained, and the employment and finances that help define our lives. It is said that cancer changes everything. Life will go on after being diagnosed with an incurable or chronic cancer, but it will require a lifetime commitment to the cancer. Long-term medical treatment will also require that we readjust to many

important social concerns. The threat of secondary cancers, disease progression and transformation, and potential disability will likely influence a cancer patient's thoughts and actions from diagnosis onward. Lifestyle adjustments that could have lasting effects on the cancer patient and his or her family will need to be considered and reconsidered. How deftly we can maneuver through life henceforth depends not only on our unique personalities but also on our particular circumstances. As with psychological issues, patients who already have sociological hurdles in their lives are generally those most dramatically burdened with further hardship.

The areas of concern we have as cancer patients may overlap or shift in importance during our life span, imposing additional threats to our health and wellbeing. Patients and their family members must first identify their area or areas of concern and then recognize the need for help and seek it out if they are to better manage these social concerns. We can obtain concrete information to help us from many sources, but sometimes it is best left for the professional to get us on track. Many patients will require support from social services staff and nurse navigators who are competent and skilled in addressing and directing ongoing care. Social services staff and nurse navigators are the best qualified to assist in these areas, yet they are not held in the same regard as the oncology team. Certainly many patients could benefit from such expertise if

Psychological and Social Needs, cont. on page 33



they knew it was available or were screened adequately for referral.

Cancer patients are not routinely screened for emotional and situational distress. Often full-blown depressive episodes can be avoided if careful monitoring is in place. Even the mildly distressed can benefit from services now in existence. Ideally, more services should be put in place, but the pressing need is for a collaborative interdisciplinary approach to cancer care. Despite commitment to their patients, a medical team of cancer care professionals typically concentrates on the medical and physical aspects where life and death decisions are the challenges and is not adequately trained to assess the psychological and sociological upheaval a patient may be experiencing.

In Conclusion

Psychosocial care of the cancer patient has not kept up with the remarkable medical advancements witnessed in cancer treatments and outcomes. This deficiency was noted by the Institute of Medicine which in 2007 issued a report entitled "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" which outlined the toll that psychological and social problems take on the cancer patient and specific goals to improve how care is directed. The Oncology Nurse Society's position statement now also includes the psychosocial needs of the cancer patient. And when surveyed, 888 people receiving treatment for cancer reported that "5 of the 10 highest unmet needs resided in the psychosocial domain."³

To be fair, we do see that some patients in the cancer community have access to services which aim to recognize the distress level of patient or caregiver. In such instances referrals are offered as needed. However, there is still a long way to go from theory to implementation of this goal, especially where shortages or distribution of health care professionals with necessary expertise further impacts the problem of access. While "cancer happens," it does not just happen to us on a biological level. Cancer patients, along with our families and our oncology team, need to understand and accept that the cancer experience, and particularly a "chronic" cancer experience, impacts us psychologically and socially as well.

Ryan Scofield Lives Strong, cont. from page 17

I was very surprised how easy it is to get started fundraising. New tools on the web make it simple for anyone to take in donations. I was also surprised at the generosity of friends and family. I found that quite a few friends who donated \$100 or more did so because they felt a personal connection to where the money was going. Instead of going into a huge pool for general cancer research, their contributions were

Care therefore must include a fully integrated life-course approach, recognizing not just the physical requirements of the patient but the psychological and sociological needs as well. These various needs are interwoven into our cancer experience, each greatly affecting the others. The cancer journey for us is a continuum of needs, and all health care disciplines should be partners to contribute to and influence our total wellbeing.

Cancer centers designed to offer exemplary care must recognize the human side of cancer and commit to a more integrative approach in the treatment of their patients. Emotional and social problems are complex. Some issues may even go beyond the current scope of practice. However, the same could be said for the complexity of cancer itself, and complexity has not halted the will and determination of our researchers and oncologists to treat the cancer more effectively. While concentrating on the one aspect of cancer care, sight should not be lost of the others.

[1] H. Ryan et al., "How to Recognize and Manage Psychological Distress in Cancer Patients" *European Journal of Cancer Care* 14(1): 2005, pages 7-15.

[2] Jimmie C. Holland, M.D., Memorial Sloan-Kettering Cancer Center, and Sheldon Lewis, *The Human Side of Cancer: Living With Hope, Coping With Uncertainty* (Harper Publishing Company: 2000).

[3] See note 1.

Wanda Huskins is a registered nurse with a psychology degree who has practiced in the field of Psychiatry and Behavioral Health for over 30 years in and around the New York City area. She was diagnosed with WM in 2008 and has recently completed successful treatments at the John Theurer Cancer Center in Hackensack, NJ, under the care of Dr. Andre Goy. Wanda Huskins can be contacted at: lymphomation@yahoo.com

This article is the first in an educational series on the Psychological and Social Issues of the Cancer Patient. Next up: "How We Can Better Adjust to Living Well with Cancer" and "How to Ask For or Find Help When We Need It."

going directly to research for my rare disease. People really responded to that concept.

I encourage everyone to try to do their own small part. Every little bit helps! Be the Cure! If anyone would like some guidance while organizing a similar event, feel free to email me at ryanscofield@gmail.com



But my first very personal exposure came from Toni, one of my Swiss collaborators with whom I was working on another drug launch in 1997. Toni confided in me that he was diagnosed with non-Hodgkin's lymphoma. Despite various treatments in Switzerland his condition deteriorated. I relayed to him the promising results from Rituxan, and he was able to begin treatment. Many a time Toni would call me in the middle of the night, Swiss time, as he claimed the steroids he was getting made sleeping difficult. During one of these sessions Toni related his strong reaction to his first Rituxan infusion which entailed tremors, profuse sweating, shortness of breath, low blood pressure – so much so that the infusion was stopped until he was stable. Apparently Rituxan is so efficient at causing death to the cancer cells that the body has a hard time handling the cell debris. It was the first time I actually spoke directly with someone who had experienced the “potential” reactions patients could get with their first infusion. Subsequent infusions, however, went well for Toni. Unfortunately, possibly due to the fact that the disease had progressed so far already, Toni lost his battle.

Several years later, however, I had my second (and more emotionally satisfying) Rituxan encounter. My wife and I were on sabbatical in New Zealand where we met another couple while at a mountain lodge. They mentioned that they were there to celebrate the fact that the husband had just escaped death. He was failing treatment for non-Hodgkin's lymphoma when his doctor put him on a “miracle drug” and now he was in remission. I asked if by any chance the drug was called Rituxan. And as he responded “How did you know?” I slipped on my “Rituxan Team” fleece vest, which I just happened to have on my chair. The profuse thanks I received was embarrassing, but I was immensely proud to have played even a small part in providing a drug which could affect lives so dramatically.

How personal can you get?

Then came my physical in early 2008: a high protein level required further investigation. Initial suspicion: multiple myeloma. I'm sure my initial response was that of all cancer patients. “This must be a mistake. I feel great. I can't have cancer.” Then the fear jumps in and you start imagining the worst.

Fortunately for me, subsequent tests determined that the diagnosis was Waldenstrom's macroglobulinemia. (I never thought I'd be happy to say I had this rare cancer, but I was when I learned that the prognosis was so much better). And, after online research, I discovered that one of the options for treatment was Rituxan! I couldn't believe it. How, after all these years working on the Rituxan project team, had I never heard of this disease as a usage of the product? Such is the fate of “orphans” – such a small patient population that no drugs are approved specifically for the disease.

At that point I did a life evaluation and allowed diagnosis to be the final motivation for something I had been considering

for a year. Time to retire! Who knows how much time we have left, so let's do all the things that are most enjoyable. Hiking, biking, tennis, a little golf, watching the grandkids grow, traveling, lots of time with family and friends. And as for WM: watch and wait.

I went to my first Lymphoma Research Foundation meeting in San Francisco and was impressed with the turnout and the scientific presentations. There in a hall full of all sorts of blood cancer patients I got my first overwhelming feeling of how important Rituxan is as a base treatment for blood cancers and the significant results it has achieved in prolonging life and improving its quality. But most impressive that day was the breakout session devoted exclusively to a very small group of Waldenstrom's patients. And the bonus of the day was Dr. Morie Gertz giving his “Garden Talk” to this small group. This was my introduction to the IWMF, and I can't believe how fortunate we all are to have this forum for patients to compare notes and have a solid cadre of top-notch physicians and researchers devoted to not only making this a chronic disease but ultimately curing it. I was hooked. The next stop was the 2010 Las Vegas IWMF Educational Forum. Again I was blown away. I've never met a group of people so involved with the science of their disease and with such interesting backgrounds. Who would have guessed this healthy-looking group of people had cancer!

Armed with a new understanding of my disease and all the latest options for treatment, I met with my own oncologist at UCSF to determine the regimen I should embark on. Although I had no nagging symptoms, I did have the occasional night sweats and was getting more and more tired due to low hemoglobin levels. We decided on the regimen of Rituxan, Velcade, and dexamethasone recommended by Dr. Steven Treon. Based on high IgM levels we decided to forego Rituxan on the first round in acknowledgment of the potential IgM spike effect at initial infusion.

The first round was no problem, just some sleeplessness the first night or so. The second round was to end with my first Rituxan infusion. I got to the infusion center wearing my Genentech Rituxan T-shirt and fleece for good luck. To the nurses – I had worked with the spouses of several of them at Genentech – I remarked, “With all the hours I devoted to Rituxan over many years, it's payback time for me.” With trepidation I recalled Toni's account of his first infusion and hoped for the best. To my relief, I handled it well and the subsequent rounds of treatment were infused rapidly.

There was no peripheral neuropathy from the Velcade or adverse reactions from the four rounds of treatment. After two rounds of maintenance in early 2011 all treatment was stopped. But, alas, although I had a good response, it was not long-lived. My numbers continue to approach those of 2010 when treatment was required.



I went to the IWMF Ed Forum in Philadelphia in June of this year, and once again I was struck by how lucky all of us Waldenstrom's patients are to have such a dedicated group looking out for orphans like us. I strongly encourage anyone who has not yet gone to one of these meetings to make a point of it. The time and money expended are more than compensated for with the information you will garner, the camaraderie you will develop with other patients, and the hope you take away that this disease can be managed and potentially cured. It also prepared me to consult with my own oncologist upon my return to begin planning for my next course of treatment, which may begin late this year or early next year. Most likely this will be bendamustine and Rituxan.

How lucky can you get?

So 4 ½ years following diagnosis, I look back and consider myself triply blessed. Number 1: to have taken a risk back

in 1981 to join a company that was based on cloning the body's own defense mechanisms to fight diseases as opposed to manufacturing chemical compounds to poison them. Number 2: to have directly benefited from one of the products I was intimately involved with during that career. Number 3: to have outstanding physicians and researchers dedicated to better control and to finding a cure for WM. The benefits derived from Rituxan and other drugs could not have happened without the physicians and researchers we have all grown to love, respect, and congratulate for taking our orphan cause under their wings and making it their own personal crusade. Their ongoing clinical efforts with already approved lymphoma drugs and their research into the underlying causes and mechanisms activating our rare condition give us reason to plan for our own promising futures.

IN THE TORCHLIGHT

"In a world where greed and egocentricity predominate, we need to step back once in a while and realize how truly fortunate we are." So wrote Guy Sherwood recently to the *Torch*, referring to the recent birth of his second grandchild. Guy was diagnosed twelve years ago at age 40. He never thought he would make it to be a grandfather.



Guy Sherwood on July 18, 2012, with his grandchildren: newborn Sidney and Norah, who was born September 25, 2010.

And today he is a grandfather twice over who is feeling fine. He just returned from a fun three-week family visit with his parents and siblings to France, the birthplace of his grandfather.

Dr. Guy is also a hard-working Trustee of the IWMF, a regular contributor to the *Torch*, and, apparently, a night-owl who stays up to the wee hours to write those frequent (and often trenchant) posts on IWMF-Talk. To top it off, he has just assumed a new position as Medical Director, Palliative Care Program, Indiana University Health Ball Memorial Hospital.

Congratulations are in order from your fellow members of the *Torch* Team and, I'm sure, from all our readers. Dr. Sherwood is truly an inspiration to us all.

Do you have a personal story, moment, event, or achievement, which made you stop recently and think

how fortunate you are? Would you share with the *Torch*? The satisfaction of children and grandchildren is only one source. Our pages are full of stories of awards, accomplishments, successful treatments, new adventures, strength of character. We can save a place in each issue to share an account, but we'll need contributions.

Write to your editor if you have suggestions at ariginos@me.com



SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

In memory of Olga Anderson:

Philip Anderson

In memory of David Applebaum:

Jeff & Linda Atlin

In memory of Marvin Arenson:

Leslie Baken

Larry & Barbara Brown

Brad & Karee Lehrman

In memory of Angel Armenteros:

Julie Grant

In memory of

Richard "Dick" Blakney:

The Allen Family

The Camp Family

DiMare Fresh, Inc.

The Massey Family

Pack 136

The Parson Family

The Simpson Family

The Thurman Family

In memory of Arlou Brahm:

Mark & Anne DeVestern, Trustees
of The Arlou E. Brahm Trust

In memory of Bob Bright:

Jerry & Barb Britschgi

In memory of Dr. Blythe Brown:

Norma B. Dunn

In memory of Jim Bunton:

Jeff & Linda Atlin

Stuart J. Boland

Troy & Janine Maxwell

Bob & Elenor Pope

Vasilis & Alice Riginos

In memory of Robert Burke:

Judith Hoy

In memory of Fred N. Chatfield:

George & Sally Gray

In memory of Frank Clark:

Paul & Joan Friedman

In memory of Gisela Crannell:

Howard & Iris Heller

In memory of Walter Dere:

Laura & Lynda Dere

In memory of Henry Dickson:

Lloyd & Sheila Hoffman

In memory of Ron Draftz:

Michael & Anne Greene

Donna Olson

Susan & Jeffrey Rubenstein

In memory of Ruth Englund:

Sherm & Phyllis Stanchfield

In memory of Marlo Gettys:

Laure Cazes Van Kerkhove

In memory of

Arnold Goldberg, D.M.D.:

Muriel Goldberg

In memory of Dr. Allan Goldstein:

Bob & Eileen Whitman

In memory of Mr. Grills:

Brad & Linda Thompson

In memory of Rev. Roy Grosz:

Brenda Holvey

In memory of Brig. S. N. Gulati:

Sneh Gulati

Paul & Aliza Rosenberg

In memory of Sam Hagendorf:

Lloyd & Sheila Hoffman

In memory of Tamara Hardy:

Gary & Sharon Dionne

In memory of Ella Hlady:

Ken & Maureen Hlady

In memory of Richard Holoff:

Judy Robinson Adler

David Bagley

Norman Bagley

Susan Holoff

Robin Bagley Jokela

Jim Kurland

Amy Robinson

Danny Robinson

In memory of Florence Huskins:

Wanda Huskins

In memory of Bernice Kane:

Carole Avery

In memory of Irene Kawaler:

Wilfred & Judith Cote

In memory of Terry Kilsby:

Kevin Kilsby

In memory of

Robert "Mickey" Knepp:

Judith E. Hughes

Jack & Mary Knepp

Irvin & Jolece Sprout

In memory of Norma A. Kuehl:

Loretta Bayne

The Bristol Myers Squibb

Midwest Sales Team

Audrey Burk

Marlene Cruikshank

Len & Carrie Langevin

Dave & Lene McKay

NutraCea

J. H. Thompson

In memory of Dorothy A. Kuveke:

Lois Shelli

The Spellman Family

Parker Schenecker

Ed & Doreen Thomas

In memory of

Dorothy A. Kuveke (cont.):

Sandy Whann

In memory of John Henry Lane, Jr.:

Robert Browning

Bob & Gail Huber

In memory of Renee Lane:

St. Jude School

In memory of Mike Lesmister:

Gay Lesmister

In memory of Pearl Locke:

Audrey Thompson

Brad & Linda Thompson

In memory of Jim Lukash:

Joe & Connie Gallo

In memory of

Dr. Marvin Mankowitz:

Armen & Mary Ellen Abrahamian

Joanne Artignani

Bob & Evelyn Baum

Norman & Elaine Blum

Everett & Diane Drugge

Janice Feldman

Don & Phyllis Goldberg

Herman Gutzeit

Robert & Judith Jacobson

Annette Lifrieri

Nina Malinak

Irvin & Phyllis Moskowitz

Mary Beth Nevins

Sharon Newman

The Pellegrino Law Firm

Chuck & Judi Polizzotti

Eric & Dana Rosen

Gwen Rosner

Sam & Terry Roth

The Robert Rovner Family

Russell & Debra Schaffer

Allan & Claire Shumofsky

The Weinstock Family

Bob West, Ph.D.

Martin & Edythe Wolf

Cary & Sora Yelin

In memory of Susan Brown Markus:

Richard Markus

In memory of Tom Moore:

Phil & Diane Yedwab

In memory of Carolyn K. Morris:

Maynard Morris

In memory of Robert Murenbeeld:

Jeff & Linda Atlin

The Hooning Family

Douglas & Lorraine Houston

Bede Ivor

Charles Murenbeeld

Walter & Antonia Murenbeeld



SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

In memory of Irv Newmark:

Kenny & Bobbie Miller

In memory of A. Edward Ooghe:

Donna Ooghe

In memory of

Dr. Richard S. Podgorski:

Dashiell Anderson

Colleen Bonker

The Laboratory Staff at Connecticut

DESPP, Division of Scientific Studies

Mary C. Courtney

Joe, Sue & Vicki Gannon

Mark Hogan

Prof. Janet A. Johnson

Carol Krebs

Edward & Mildred Norton

Pace University

David Prutting

Ted & Brenda Strauss

Kim Stylsinger

In memory of Patricia Ready:

John & Patricia Diego

Yvette Duhamel

Robert Hanley

Nancy Horton

In memory of Neil Rehrer:

Keith Rehrer

Susan Rehrer

In memory of Lorraine Ripberger:

Alfred & Susan Brunner

Jim & Kathie Demetre

Diana Kemper

Larry & Jodi Maushart

James & Janet Reis

John & Cindy Ripberger

Susan Sayers

Frank & Connie St. Charles

In memory of

Elizabeth Mondello Rizzuto:

Air Products

The Al-Juraid Family

Calvin & Jo Ann Balencie

Mike, Vicki & Cody Hoormann

In memory of Ralf Horst Roberts:

Monica, David & Rachel Beck

In memory of Dolores Rosenbaum:

Merle Weston

In memory of Judith Rosencranz:

Robert Rosencranz

In memory of Alex Ross:

Brenda Holvey

In memory of Stanford Rubin:

Bob & Eileen Whitman

In memory of

William A. Scaring, M.D.:

Carole Avery

Carole Scaring

In memory of Donald Schwartz:

Bob & Eileen Whitman

In memory of

Mireille Beaulieu Toutant:

Sylvie Berube

Louise Davis

Jocelyne Delisio

Sophie Deschenes

Jacques Gaudreau

Lucie Laperle

Line Lapointe

Helene Lasnier

Pharmacie Fortier

Johanne Provencher

Maureen Quig

Denis Robert

In memory of Angela Mary Tydgat:

Baron & Diane Biedenweg

Anne Claeys

Ruth Anne & Brenda Cochran

Jo Ann Cummins & Family

Dennis L. & Sheryl M. Harper

Brent & Kathy Holaway

Stephan R. & Karen Lehman

Gary & Sheila O'Dell

Gordon Schermer

Mark & Linda Sevy

Michael S. & Ruth A. Story

Dennis & Patricia Tushla

Richard & Linda Van Hoedt

In memory of Nicholas Wyman:

Monika Ebi

NERO Employees Club - BOP

In memory of Joan Zeidner:

Dan & Karen Pindzola

In memory of

Jan Howard Zimmerman:

Brad's co-workers at HQ Claims,
Cincinnati Insurance Company

Nancy Kauffman

Don & Margie Maurer

Gerald & Peggy Nevland

Robert Robinson

Robert Robinson, Sr.

Eddie Southard

William Spencer

Marilyn Wollett

Chalmers & Judy Zimmerman

SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

In honor of John M. Albert:

Lori Tullis

In honor of Thomas M. Baker:

Ted & Almie Baker

In honor of Mary Ellen Bowering:

Spike & Alex Buckley

Michael Sugarman

In honor of

Christian Britschgi's birthday:

Jerry & Barb Britschgi

In honor of Don Brown:

Ormel & Lois Prust &

The Chicago Area Support Group

In honor of Mindy Caplan:

Daniel Caplan, M.D.

In honor of the

Chicago Area Support Group:

Various backers of the

Ryan Scofield Half Marathon

In honor of Carol Classe:

Students from the Duchesne

Academy of the Sacred Heart

In honor of Michele Clewell:

Christine Walsh

In honor of Maria Colosi:

Gia Colosi

In honor of Arlene R. Davis:

Mary Ann Chartrand

In honor of Bruno Dominelli:

Dale & Lori Donnelly

Isaac Habraken

Dan Shannon

Fred & Dianne Sinclair

In honor of James Endler:

Dawn Strand

In honor of Joe Gallo:

Michael Gallo

In honor of

Linda Geary's 70th Birthday:

Leo & Jane Amato



SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

In honor of Bill Hannaford:

Joe Bell
Katrina Christie

In honor of Carl Harrington:

Vimukti Victoria Aslan
Samuel Harrington

In honor of

Arlene & Jeremy Hinchcliffe:

Andrew & Margaret Stephens

In honor of Jack Honaker:

Sarah Fitori

In honor of Larry Horowitz:

Claire Auckenthaler
Cheryl Doran

In honor of Wanda Huskins,

Author Extraordinaire:

Ray Dalio
Jeff Prupis

In honor of Marcia & Glenn Klepac:

Marikay Boraca

In honor of Jonathon Klinck:

Cynthia Ruhl

In honor of

Jonathon & Cynthia Klinck:

Dr. Lawrence Brody

In honor of Tony Knight:

Hazel Blackburn

In honor of Joy Kramer:

Doris Kramer

In honor of David Marx:

The Isaac Family

In honor of Judith May:

Kimiko Ise Abramoff
John M. & Gloria Albert
Raphael Altman
Harold & Colleen Ambauen
Michael John & Yvette Andrews
Jean Arndt
John & Paula Austin
Judith Austin
Gayle & John Backmeyer
Marilyn & Allan Bandel
Jo-Ann & Frank Baron
Gary & Yvonne Baur
Robin Benjamin
Susanna Bensinger
Linda Benson
Joseph Bergman
Tom Bichsel
Terry Bilsbrough
Lou Birenbaum
James C. Black
Jonathan Blake
Jerry & Harriet Block
Janet & Geoff Bone
Marcia & Allan Bosswick

In honor of Judith May (cont.):

Clement & Patricia Boudreau
Barrie & Kay Bowen
Pete & Barb Boyse
Ronald & Mary Jane Branscome
Donald Bratt
Don & Mary Brown
Susan Brown
Charles & Dorothy Bryan
Elo A. & Carolyn Buenger, III
Barbara Bunton
Arlene & Alfred Carsten
Leonard Chirchigno
Bill & Lola Christianson
Thomas Chused
Reg Clifford
Maria & Tom Colosi
Christina Conley
Roberta J. Dabney
Arlene Davis
Robert & Jeannette Dawson
Steven De Mello
Raenalle DeGidio
Phillip & Helen Deverman
James Dimino
Howard & Joanne Donley
Cathy Drexler & Wade Mueller
Everett & Diane Drugge
Linda Duraney
Fred Ebeling
Jean Edmark & Richard Float
Otto & Carol Ehlers
Larry J. & Verna Ellis
Marianne & Ulrich Engler
Terrie & Mike Eshleman
Barbara Felzien
Danita Findahl
Rita & George Freeland
Geetha Gangadharan
William Andrew & Nettie Garroch
Leon Gauss
Marty & Arlene Glassman
Pam Glossi
Lila Gobbell
Barbara Goll
Donald Graham
Hugh Graham
Patrick & Susan Grant
Walter & Florence Grassler
Barbara Gregory
Daniel Griswold
Bertha & Seymour Grodstein
Catherine & Joseph Gustaitis
Harriet & Samuel Hand
Virginia Hanson
Dave & Flo Hare
James & Shirley Harney
Carl Harrington
Mary & Humphrey Hartmankok
Gary Hill
Eric Michael Hilt

In honor of Judith May (cont.):

Arlene & James Hinchcliffe
Barbara Howell
Shirley M. Huett
Pavel Illner, MD
Edward Isaac
K. Edward Jacobi &
Katharine McCleary
Forrest Wayne Johnson
Shirley & Cameron Johnston
Kevin Kimber
George King, III
Sanford Kingsly
David & Penny Kirby
Charles Koch
William & Joyce Koontz
Rosalie Kotrba
Tom & Bev Lacey
Madeleine & Bertrand Lacombe
Robert Lallamant
Delores Lambert
Dean & Shelva Lane
Donald & Jean Ledenbach
Rowland & Tobbie Leep
George & Norma Leyva
Ilene & Salvatore Lipari
Stephen Locascio
Richard B. Lohrer
Rita & Homer Lowenberg
John Madura
Gary & Elena Malunis
James & Gillian Mason
Virginia-Kay Massara
Neil & Joyce Massoth
Emily & Peyton McLamb
Sandy & Tom Meienberg
Paula & Chester Meisel
Mike & Margie Miller
Ulla & Max Molin
Dan Morrissey
Blanche Moss
Geoffrey William Mould
Carleen Moyer
Karen & Fred Naase
Vincent Natali
Catherine Naylor
Leslie Neustadt
Amelia Nisser
Barbara & Michael Noonberg
Jimmie Nutt
Marjorie Oberlander
Catherine Oliphant
John & Penelope Paasch
Sandra & Gene Patton
Valerie & John Petelin
Kenton Peterson
Gerry & Joy Pierce
Karen & Dan Pindzola
Satish & Jayshri Prasad
Rick & Ruth Pritchard
Sandra Proctor



SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

In honor of Judith May (cont.):

Ormel & Lois Prust
Elizabeth Pye
Connie Reed
Marguerite Regan, Ph.D.
Gil & Margaret Reyes
Bernice L. Rhine
Lee Rickard
David Robbin, MD
Kathleen Salvas
John & Ruth Sayer
Carole Scaring
Don Schade
Ed & Virginia Schaffer
Sandra Scheibe
Lorraine Schick
Dr. Stephen Scola
Dale & Kazuko Scott
Ed & Marilyn Seastrand
Guy & Faith Sherwood
Addie & Kent Siegel
Seymour & Estelle Siegel
Marylou Snyder
Sandra M. & Kent Solomon
Shara & Dave Stills
Lee Stratman
Charlotte M. Swanson
Bernard & Rita Swickow
Phyllis & James Swint
Bill & Wenchi Taylor
Lorraine Tenpas
Linda Tollner
Alice Tracey
Ron Treptow
William Turner
Mary & Peter Turnquist
Bernard Tyrell
William Voelkle
Mike & Deloris Vogel
Sheldon Welles
Richard & Carolyn Wieneke
Marcia & Ken Wierda
Johanna Williams
Donald H. & Kate Wolgemuth
Elaine & Lane Wolman
James & Joyce Yeager
Charlotte & Bob Zerfoss

In honor of Catherine McClounan:

Michael Iloo
Elizabeth Rudolph

In honor of

Claire Lior's Bat Mitzvah:

Donna Kirz

In honor of Christopher Moakley:

Julie Moakley

In honor of Marie Navarra:

Joy Crabb

In honor of Molly O'Connell:

James & Marie Anstett
Edward & Kathleen Healy, Jr.
Bill & Ginger Hodges
Jane Macgreevy
James & Evilo Moore
James & Maureen Reis
Brian & Nancy Vitello
Salvatore & Connie Vitello
Richard & Susan Williams

The 10th Annual O'Soro Family Fundraiser for WM:

Mary Ann, Gregory & Katcher Afarian
Lisa & Brian Blackwell
Claire & Paul Bolger
Scott & Jill Conti
Sean & Diane Daly
Kathleen & Joseph de Mita
Michele & Jason Eldridge
Robert & Helen Gard
Aimee & Jesse Hammond
Lance & Diane Hoenig
Colleen Hughes
Matthew Keating
Elizabeth & Charles Kochakian
Jason Lawton
Lisa Lawton
Lynn & John Lopes
Michael & Amy Morrissey
Elizabeth Myers
N & D Transportation Company, Inc.
Francis & Dorothy O'Keeffe
Charles & Nancy O'Soro
Carol Nancy Scott
Jim & Carol Shiner
Douglas & Karen Storrs

In honor of James Paxton:

Lynda Nielsen

In honor of Ron Payne:

Steve Payne
Rob & Jennifer Schiavone

In honor of Elizabeth Pye:

Robert Pye

In honor of Anna Mae Quitter:

Janine Quitter

In honor of

Jon Randall's 60th Birthday:

Bill Harrington

In honor of Alice Riginos:

Eleanor Swift

In honor of Jackie Romanello:

Tom Romanello

In honor of Robert Rosencranz:

Leslie Herzog

In honor of

Audria Schnitzer's Bat Mitzvah:

Donna Kirz

In honor of Michael Sesnowitz:

Craig Sesnowitz

In honor of Robert Shustak:

Donald & Rose Shustak

In honor of Richard Swain:

Rosie Babel

In honor of Dr. Steven Treon:

Anna Roche

In honor of Elaine Van Bloom:

Fred & Dolores Pernerstorfer

In honor of Bert Visheau:

Bertram Visheau

In honor of Ubaldo Vitali:

Val Iacovantuno
John & Diane Vantuno
Nicole, Steve, Leo,
Calvin & Kyle Wagner

In honor of Sam Vitaro:

Stela Mandel

In honor of Volunteers

that Support the IWMF Cause:

John Paasch

In honor of Marcia Wierda:

Kathleen Sue Brandt
Tom & Terri Brandt
Lynelle Brown
William & Joyce Buis
Troy Bytwork
Paul & Heather Clark
Thomas & Tamara Elhart
Go Technology Company, Inc.
Evelyn Hamberg
Darryl Lokers
Thomas Mannes
Marty & Tricia Maxim
Steven & Stacy McKinney
Matthew Mehling
Mary A. Olsen
Jeffrey & Karri Ratuszny
Douglas & Elaine Schaedler
Linda Taylor
Betty Lou Terhaar
Jason Tooker
Andy & Tracie Wierda
Ken Wierda
Timothy & Sara Bentley Wierda

In honor of Robert Worth:

William Worth, Jr.



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

Change of Address

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

SAVE THE DATE!

IWMF 2013 Educational Forum

May 17 - 19

San Diego, California

The 2013 Ed Forum will be held in downtown San Diego at The Westin Hotel.
We've got a great rate at \$129 a night and that rate is good for 3 days before
and 3 days after the meeting. Further information forthcoming.

Why not plan a vacation in beautiful San Diego?