The IWMF Board of Trustees is pleased to announce the election of Carl Harrington to the position of President of the International Waldenstrom’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 Mills.

Carl Harrington,
President-Elect of the IWMF.
INTRODUCING CYNCIA 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.
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 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). Intervventional 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
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 pace 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
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:


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 Philadelphia (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
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 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. 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 Auburndene – 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.

Recipient 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.


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


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
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 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 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
“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.

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!
The Seventh International Workshop on Waldenström’s Macroglobulinemia (IWMW7) 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 a special guest presentation (by Dr. Bruce Cheson – director of the very first IWWMM meeting in Washington, D.C., in 2000) resulted in a very busy and comprehensive conference.

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 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...
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 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 Cytoxan/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
“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. 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 the diagnostic classification of an adjustment disorder. The anxiety felt will become severe and barely tolerable. Patients with severe anxiety complaint 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 the diagnostic classification of an adjustment disorder. The anxiety felt will become severe and barely tolerable. Patients with severe anxiety complaint of constant tension and appear restless and hypervigilant. They complain of insomnia, poor appetite, apprehension, and will worry and brood.

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
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.

**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.
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 ≥ 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 Gleevec, 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 IMGN529 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 IWMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

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 IWMF.

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 IWMF 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.

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 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 IWMF.

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RYAN SCOFIELD LIVES STRONG, cont. on page 17
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, soppressata, and capicolla; 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 smokey 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 of 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. from page 17

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. Hmm, 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 brrrr 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

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!
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.

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 599, 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

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, Cytoxan 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 dent 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!
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 Ghorbrial’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. 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
the Chicago Allstate Half-Marathon with some friends (see page 17). This well organized event demonstrates how IWMF support groups can make a difference! In the photo above, Don and Mary Brown model the “Be the Cure” T-Shirts designed 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 IWMF senior development officer Dave Benson. If time permits, the “Ask the Doctor” 2012 Educational Forum video will be shown.

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.

The IWMF 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 IWMF as a recipient in honor of a close friend of Mr. Baker who was recently diagnosed with WM. The IWMF 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 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
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THE LIFELINE

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

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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.

And that day has come. With the creativity and strengths of Carl Harrington and all fourteen members of the current Board of Trustees the IWMF 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

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

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.

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 IWMF and a local support group in the greater Philadelphia area. He has served on the IWMF 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.

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 IWMF website.

As a 12+ year WM survivor, I wish to personally thank the workshop organizers: Drs. Kenneth Anderson, Nikhil Munshi, and Steven Treon of the Dana-Farber Cancer Institute, Boston, MA. Many thanks to the sponsors of the event: Celgene, Cephalon, Millennium, Onyx, IWMF, 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 IWMF 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.

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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.

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 IWMF in the mid 1990s and became an IWMF 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 IWMF 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 IWMF.

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 then one in ten receives a referral for help.”

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
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.”

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. 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.


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.”

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 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
Imagine This, cont. from page 13

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.
Imagine This, cont. from page 34

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. 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
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Carole Avery
Carole Scaring

In memory of Donald Schwartz:
Bob & Eileen Whitman

In memory of Mireille Beaulieu Toutant:
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Louise Davis
Jocelyne Delisio
Sophie Deschenes
Jacques Gaudreau
Lucie Laperle
Line Lapointe
Helene Lasnier
Pharmacie Fortier
Johanne Provencher
Maureen Quig
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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 Zieider:
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
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SINCE FEBRUARY 2012, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM’S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

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Lori Tullis

In honor of Thomas M. Baker:
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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
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:
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Sarah Fitori

IN HONOR OF LARRY HOROWITZ:
Claire Auckenthaler
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IN HONOR OF WANDA HUSKINS,
Author Extraordinaire:
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IN HONOR OF MARCIA & GLENN KLEPAC:
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IN HONOR OF JONATHON KLINCK:
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JONATHON & CYNTHIA KLINCK:
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In honor of Jon Randall’s 60th Birthday:
  Bill Harrington

In honor of Alice Riginos:
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In honor of Jackie Romanello:
  Tom Romanello

In honor of Robert Rosencranz:
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In honor of Sam Vitaro:
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In honor of Volunteers that Support the IWMF Cause:
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In honor of Marcia Wierda:
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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.

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