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DOCTOR ON CALL: JEFFREY MATOUS, MD



Dr. Jeffrey V. Matous

Dr. Jeffrey Matous is the Medical Director at the Colorado Blood Cancer Institute and Clinical Professor of Medicine at the University of Colorado. After graduating from Medical School in 1985 from the University of Washington, he completed an Internal Medicine residency and chief residency at the University of Colorado. Fellowship training in Hematology and Bone Marrow Transplantation followed at the University of Washington and the Fred Hutchinson Cancer Research Center. Since 1994 he has worked in private practice in Denver, focusing on the care of patients with blood cancers. He is an enthusiastic educator and a member of committees of both the American Society of Hematology and the American Society of Clinical Oncology. He co-chairs the Sarah Cannon Myeloma Committee and is a Board member of the Rocky Mountain Chapter of the Leukemia & Lymphoma Society (LLS), having been honored with the Chairman's citation for LLS volunteerism in 2012. Dr. Matous has been a past contributor to the Torch and a presenter at two IWMF Educational Forums, including the most recent one in Providence where he spoke about treatments for relapsed/refractory WM and co-moderated a breakout session on ibrutinib.

IBRUTINIB IN WM

The story of ibrutinib (Imbruvica) is perhaps one of the most exciting in the annals of Waldenstrom's macroglobulinemia (WM) and serves as a spectacular example of how scientific perseverance coupled with the skill of talented physician scientists can change the lives of patients in a very real way.

In order to understand the importance of ibrutinib in WM, it is helpful to review some basic biology of the disease.

WM is a type of B-cell non-Hodgkin lymphoma (NHL), one of dozens. One feature of lymphomas, and indeed cancer in general, is that the abnormal or cancerous cells do not follow the rules that normally govern the behavior of healthy cells. We know various ways in which B-cell lymphomas and therefore WM misbehave. The production and lifespan of healthy cells is carefully and beautifully orchestrated. The body maintains a perfect inventory of these B-cells, because they are produced and turned over in a tightly regulated fashion. In WM the cell that produces healthy B-cells and plasma cells (a very mature type of B-cell) undergoes one or several mutations (changes in the DNA inside the B-cell that were not present at birth but which were acquired by chance), and those mutated cells no longer follow the normal rules. They grow more than they ought to and fail to turnover or die when their time is due. The end result is that WM patients accumulate far too many cancerous cells (lymphoplasmacytic or LPL cells), which produce the typical signs and symptoms characteristic of WM.

We will focus on the over-production side of things since that is primarily how ibrutinib helps WM patients.

This abnormal behavior is largely influenced by a series of molecular steps, the end result of which is to grow and divide uncontrollably. Think of a row of dominoes. The first domino is outside

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Doctor on Call, cont. from page 1

the WM cell (a “receptor”) but most of them are inside the cell (“intracellular signaling pathways”) and connect all the way to the core or nucleus of the cell, where the chain of falling dominoes results in changes in the DNA – which make the cell cancerous. In WM and other B-cell lymphomas, there are a few critical paths of dominoes, and the problem is that the dominoes tip over *on their own, and just keep doing so*. The scientific term for this is “constitutively activated,” that is “always turned on.”

The reader may be asking what any of this has to do with ibrutinib. There is a critical protein, specifically an enzyme, inside B-cells called BTK (Bruton’s tyrosine kinase) that is involved in the growth and development of normal B-cells. In several B-cell cancers, including WM, there is too much of it, and this is a big part of what fuels those dominoes to keep tipping over, causing the cancer cells to be overproduced. There is also an important molecule called the B-cell receptor (BCR) sitting on the outside or surface of the cell, and in these cancers it is always turned on when it shouldn’t be. *BTK helps translate that message* (domino effect) to the DNA inside the nucleus. In other B-cell cancers such as chronic lymphocytic leukemia (CLL), it has long been recognized that inhibiting BTK can kill the cancer cell (apoptosis). Ibrutinib inhibits BTK, was tested in CLL and in another B-cell blood cancer called mantle cell lymphoma, shown to be effective, and subsequently approved by the US Food and Drug Administration for those cancers.

None of this went unnoticed by Dr. Steve Treon at Dana-Farber Cancer Institute in Boston. Dr. Treon and his group made the most important discovery to date in WM when they found a mutation in a gene called MYD88, which was present in virtually every individual with WM. It turns out that MYD88 is one of those critical proteins inside certain cells that helps those cells over-produce when mutated. MYD88 does this by associating with a lot of other proteins inside the cell, including BTK! Dr. Treon then postulated that perhaps inhibiting BTK (ibrutinib was out there being studied in other blood cancers) might help WM patients, and he designed a clinical trial to address that question.

Dr. Treon, along with collaborators at Stanford University and Memorial Sloan Kettering, treated WM patients who had experienced a relapse after having had at least one previous chemotherapy treatment with 420 mg daily of ibrutinib.

Beginning in May 2012, 63 patients were enrolled in this clinical trial. It is important to understand what kind of WM patient was treated in this study. All patients had previously been treated for WM. They could not be too ill or too frail and had to have reasonably healthy blood counts. They could not have been taking a blood thinner called warfarin. They could not have lymphoma in the central nervous system.

Doctor on Call, cont. on page 3



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The results were impressive and published in the *New England Journal of Medicine* in 2015. By one month most patients were showing a benefit. Nine of out 10 patients responded favorably to ibrutinib, and 7 out of 10 had a dramatic improvement. IgM levels plummeted in most patients, and those who were anemic generally had a noticeable improvement in their anemia and energy levels. Side effects were generally mild and the drug was well tolerated. The drug was continued so long as it was working and side effects were acceptable.

Dr. Treon and colleagues further showed that by determining the status of two critical mutations in their patients – MYD88 and CXCR4 – they could define those patients more likely to benefit from ibrutinib treatment. The patients who had a mutation in MYD88 but not CXCR4 did the best, followed by those who had mutations in both MYD88 and CXCR4. The latter group had a lower chance of a really good remission and it took longer to see the maximal benefit. This work led to FDA, Canadian, and European Commission approval of ibrutinib not only for those patients who had been previously treated and experienced a relapse, but also for patients who had never had treatments.

WM PATIENTS HAVE MANY QUESTIONS ABOUT IBRUTINIB

Because of the increasing clinical use of ibrutinib in WM and the fact that we are now gaining more experience with it, patients who are already on the drug or who are considering starting it have many questions. I have attempted to provide answers to some of the most common ones asked by patients in my practice, on IWFM-Talk, and at the recent IWFM Educational Forum.

General Questions about Taking Ibrutinib

What is the dose of ibrutinib?

The recommended dose is 3 capsules (140 mg each) daily taken all at once (total 420 mg). Ibrutinib can be taken with or without food with a glass of water at roughly the same time each day. Some patients prefer it earlier or later in the day depending on side effects such as nausea or dizziness, and it is OK to switch – just try to be consistent.

Is 420 mg really important? Don't lesser doses of ibrutinib work just as well and have fewer side effects?

We really believe that in order for the drug to most efficiently work against BTK, 420 mg is strongly recommended. The scientific reason for this relates to a concept called “BTK occupancy,” which basically means that you want to use enough of the drug to effectively block the BTK sites in the B-cells. Some patients require reductions of the dose due to side effects, but we try and give the full 420 mg whenever possible. In a recent study called iNNOVATE, few patients required modification of the dose, and the most common reasons for doing so related to gastrointestinal side effects.

Is ibrutinib the best initial treatment or mostly used for relapsed WM?

Almost all of the data supporting the use of ibrutinib come from studying it in patients with relapsed WM. That is, they have had prior chemotherapy for WM. That is generally how I use it. Outside of a clinical trial, I will consider it as initial treatment for older, frailer WM patients who, following my assessment, appear to be able to tolerate the drug.

Once I start ibrutinib do I have to take it forever?

Right now we believe that as long as the drug is working and tolerated it ought to be continued indefinitely. Ibrutinib works a little bit like a light switch – when the drug is stopped all the lights are turned back on, and we have seen patients who stop the drug experience fairly rapid rises in their IgM levels.

Is ibrutinib ever combined with other chemotherapy treatments?

It was approved by the regulatory agencies to be used as a single agent, all by itself. Clinical trials are addressing combination usage. One large study is testing ibrutinib in combination with rituximab. We will see more combinations being studied in the future.

Do I need to inform my doctor if I am taking herbal or alternative treatments when I am also on ibrutinib?

Absolutely! Many supplements (such as ginkgo biloba) can lessen the benefits of ibrutinib, and some (such as fish oil) can increase the risk of side effects.

I have heard that I have to know my MYD88 and CXCR4 mutational status before I can start ibrutinib? Is that really true?

This is a point of debate among WM specialists. We know that WM patients who have mutated MYD88 and unmutated CXCR4 respond best to the drug, but to be honest, I try the drug to see if it works. Other WM docs like to test for those mutations first.

Important Information to Know When You Are Taking Ibrutinib

Do I need to temporarily stop ibrutinib when I undergo surgery or other procedures?

Yes. For minor procedures withhold the drug for 3 days before and 3 days after the procedure. For major surgery we make it 7 days before and 7 days after. These are general recommendations, and other physicians may have slightly different ones.

Are there any foods which should be avoided when I am on ibrutinib?

We recommend avoiding grapefruit, star fruit, and Seville oranges at all times while you are on ibrutinib. They make the ibrutinib too strong and could significantly increase

side effects. St. John's wort theoretically could lessen the effectiveness of ibrutinib.

I have arthritic pain and take NSAIDs (such as ibuprofen). Is it safe to take NSAIDs with ibrutinib?

This is a tough one. These drugs can act as blood thinners and must be used with caution and only with the approval of your physician.

Side Effects of Ibrutinib

What are the most common side effects of ibrutinib?

1. Rash or cracked brittle nails
2. Diarrhea (~40%, rarely severe), decreased appetite, heartburn
3. Bleeding or bruising
4. Atrial fibrillation (not so common, ~5%)
5. Lowering of normal blood counts
6. Aches and pains
7. Dizziness (~10%)
8. Tiredness

Tell me more about bruising and bleeding caused by ibrutinib. If my doctor wants me to take blood thinners (for a blood clot history) are there any I can take when I am also on ibrutinib?

Ibrutinib has blood-thinning properties resembling aspirin. Some patients experience a lot of bruising on ibrutinib whereas others have absolutely none. In the most important clinical trials with ibrutinib, patients taking warfarin were not allowed to participate in the study. I tend to avoid warfarin and, if need be, use other types of blood thinners for patients who require them. I do not start ibrutinib in patients with a history of blood clots until I know that they are stable and can tolerate their blood thinner.

Can ibrutinib cause or worsen high blood pressure?

I think it does and can even cause it in patients who have been on the drug a long time. It can be managed in many ways, including the normally used blood pressure medications.

Can ibrutinib cause atrial fibrillation? If I had atrial fibrillation in the past, is it safe for me to take ibrutinib?

It can cause atrial fibrillation but the risk is low, about 5%. Patients with a history of previous atrial fibrillation of course carry a higher risk of recurrence. Certain medications to combat atrial fibrillation can interact with ibrutinib, and vice-versa, and this must be kept in mind when selecting a treatment for the arrhythmia.

I have been taking ibrutinib for over a year and now have cracked and brittle nails and flaky skin. Could that be due to ibrutinib? Is there anything I can do about it?

Yes, it is the ibrutinib. Biotin may help the nails. Use alcohol-free moisturizers. Sometimes we will recommend a light steroid cream for particularly bothersome skin rashes. Keep the nails short.

Other Commonly Asked Questions

Does ibrutinib cause IgM flare?

No, at least not when used by itself.

Can ibrutinib be used in hemodialysis patients?

We do not know and I have not done so.

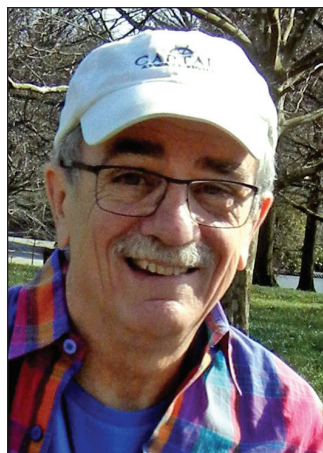
Please keep in mind that everyone's WM is different and that the effectiveness of ibrutinib or any other treatment varies greatly among WM patients. There is no substitute for staying really well informed and communicating with your health care team.

I would like to thank the IWME, our patients, and especially Megan Andersen, NP, and Sonja Bren, RN, here at the Colorado Blood Cancer Institute, who have taught me so much about caring for WM patients. Thank you also to Jorge Castillo, MD, of Dana-Farber Cancer Institute in Boston for reviewing this article.

Have Your Say

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

PRESIDENT'S CORNER: "REACHING FOR THE MOON"



Carl Harrington, President

Do you remember where you were on June 5, 2013, when Neil Armstrong said, "That's one small step for man, one giant leap for mankind"? Probably glued to your TV, just like I was.

Well, strap in, we're headed for new realms with *Cancer Moonshot*. In his 2016 State of the Union address, President Obama put Vice President Joe Biden in charge of a new national effort to end cancer as we know it. The goal of *Cancer Moonshot* is to "double the rate of progress toward a cure – to make a decade of advances in cancer prevention, diagnosis, treatment, and care in 5 years." Joe Biden is working right now to "clear the launch pad" by getting to the bottom of current inefficiencies, delays, and illogical practices. While I applaud the *Moonshot* initiative, I must also ask what it means for a little orphan disease like ours.

In the short term, it probably doesn't mean much. However, the IWMF has already been working on more practical steps to "reach the moon" via the IWMF-LLS Strategic Research Roadmap. Our Roadmap strategy aims to make rapid advances in prevention, diagnosis, treatment, and care of WM. And we have already taken the first steps. As you'll see below, we have our own target, our own "engineers" (the

Roadmap team), our own "rockets" (the four pillars of the Strategic Research Roadmap), and our own test projects (the first approved Roadmap proposals). In total, we expect to unleash resources to rewrite the current knowledge about WM. Our goal isn't the moon. In Star Trek terms, our goal is to "boldly go where no man has gone before," namely to a cure for WM.

Back here on Earth, let me close by saying:

- The 2016 IWMF Educational Forum was a huge success. We had record attendance of more than 300 WMers. Attendees rated the Ed Forum at 4.8 out of 5; we really couldn't do better than that! Read more about the 2016 Ed Forum on pages 15 and 21. Then make plans now to come to Phoenix, AZ, on May 19-21, 2017, for the 2017 IWMF Educational Forum and see for yourself why an Ed Forum is so worthwhile.
- If you ever thought about doing a fundraiser for the IWMF but needed some help, we've made it much easier. Visit the IWMF website at iwmf.com/how-you-can-help/fundraise-iwmf to learn how you can run, walk, bike, have a dinner or tea, or whatever you imagine to fundraise for the IWMF.
- And, speaking of the website, all of the photographs posted there are of real WMers. We'd like to add your pictures. Please contact IWMF Webmaster Barry Nelson at BarryNelson@alum.MIT.edu to add your photo.

Stay well and keep trekking,

Carl

IWMF-LLS STRATEGIC RESEARCH ROADMAP

BY CARL HARRINGTON, IWMF PRESIDENT

Exciting news! The Strategic Research Roadmap jointly sponsored by the Leukemia & Lymphoma Society and the International Waldenstrom's Macroglobulinemia Foundation is rolling out successfully in three directions:

1. The 2016 Roadmap Conference

The second IWMF-LLS Strategic Research Roadmap Conference was held May 20-21 in New York City. This meeting focused upon updates and progress in the four areas identified at the 2015 meeting:

- **Signaling:** WM cells need to communicate to survive. *How can we interfere with that communication?*
- **Tumor Microenvironment:** WM cells are creatures of their environment (the bone marrow where they develop). If we can better

understand the environment or "neighborhood" where our WM cells live, we can alter the neighborhood so that it no longer enables WM cells to live and thrive. *How can we expel WM cells from their cozy homes and create "death by homelessness?"*

- **Immunology/Immunotherapy:** WM is a wily foe. WM cells often "hide" in their environment and are not recognized as a threat by our immune system. If we are able to understand the immune checkpoints – proteins that prevent the immune system from attacking – we may be able to devise antibodies that inhibit these checkpoints. *How can we unleash the immune system to kill WM cancer cells?*

IWMF-LLS Strategic Research, cont. on page 6



The second IWMF-LLS Strategic Research Roadmap Conference was held in the Uris Faculty Club of Weill Cornell Medical College. Those attending (from l to r) were: Dr. Kimon Argyropoulos, Carl Harrington, Dr. Richard Furman, Dr. Stephen Pals, Dr. Lia Palomba, Dr. Aneel Paulus, Dr. Zachary Hunter, Dr. Robert Kyle, Dr. Roger Owen, Dr. Steven Treon, Dr. Stephen Ansell, Dr. Tanya Siddiqi, Dr. Ramon Garcia Sanz, Dr. Steven Rose, Dr. Adrian Wiestner, Dr. Morton Coleman, Dr. Guy Sherwood.

- **Omics:** Using an analogy drawn from computers, you can think of genomics as the computer hardware (your PC, Mac, or whatever) and epigenetics as the software (Word, Excel, etc.) for manufacturing proteins from genes. *What can we learn about genomics, epigenetics, and WM mutations that will help us cure WM?*

Dr. Lee Greenberger, Chief Scientific Officer of LLS, again led the 2016 meeting. The scientific co-chairs were Dr. Steven Treon of the Dana-Farber Cancer Institute (DFCI) and Dr. Stephen Ansell of the Mayo Clinic.

The format of the 2016 meeting followed that of 2015: Day One was devoted to presentations and discussions in each of the 4 areas identified above, while Day Two focused on individual presentations by selected pharmaceutical companies. One major difference in the 2016 agenda was the inclusion of an outside expert in chronic lymphocytic leukemia (CLL), Dr. Adrian Wiestner from the National Institutes of Health, who shared his expertise in that disease and the implications for WM. Very enlightening!

Overall, attendees were very enthusiastic about the amount of progress made in the last year. Dr. Ansell summed up the overall sense of the meeting by saying, “Going into the meeting, I was a bit concerned that it might be too similar to last year. However, I was delighted by the progress, the new discussions, the new details, and the new information. I left feeling we were making real progress and was impressed with the commitment shown by everyone attending.”

The meeting took place in the Uris Faculty Club of Weill Cornell Medical College. In the photograph of the distinguished attendees at the 2016 meeting above, note that the meeting space was filled with rare and antique medical devices, an inspiration for us all as we sat there creating a new future in cancer research.

2. The 2015 Request for Proposals

In November of 2015, we issued a request for proposals (RFP) that we developed jointly with LLS. We were thrilled to receive 18 proposals from around the world. In the past, we have received only one, two, or maybe three, proposals in a year.

- 7 of the proposals were from researchers outside the US (1 from Australia, 1 from France, 1 from Germany, 2 from Italy, and 2 from the Netherlands).
- 12 of the proposals were from institutions that had never before applied for an IWMF research grant.
- 14 of the proposals were from researchers whom we had never funded before.

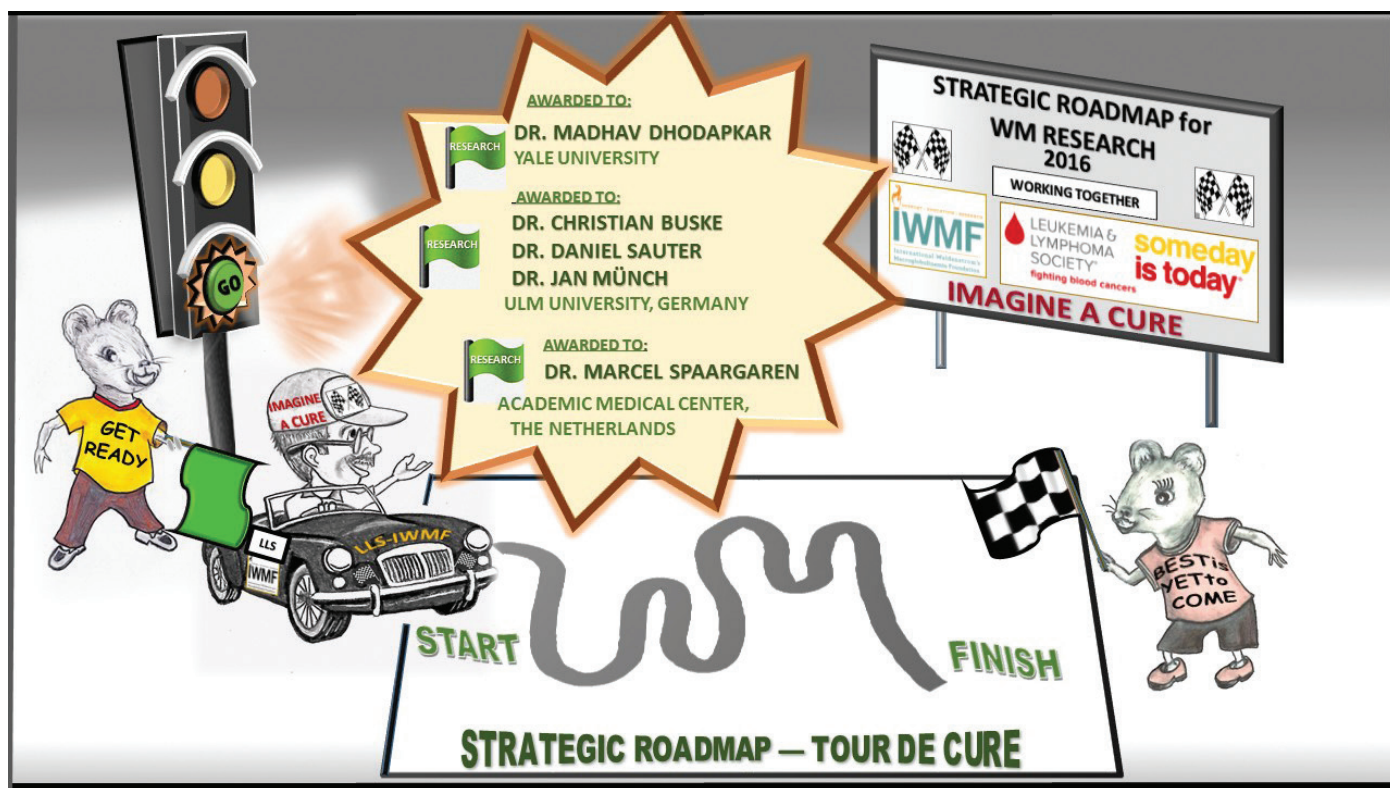
We are delighted that **eminent researchers worldwide are competing for your money to do research in WM.**

An independent panel of WM researchers from around the world evaluated all of the proposals. Dr. Ansell led this process, which followed NIH (National Institutes of Health) rules. Dr. Greenberger of LLS commented as follows on the evaluation process: “We were delighted with the quality of the proposals as well as the rigorous evaluation procedures, similar to NIH, that led to the selection of the awardees.”

At its June 2016 meeting, the IWMF Board of Trustees approved renewal of Dr. Steven Treon’s project entitled “Targeting MYD88 Assembly and Downstream Signaling in Waldenstrom’s Macroglobulinemia.” At the same meeting the Board approved funding for the three top-ranked Roadmap Research Proposals. These proposals are:

Dr. Madhav Dhodapkar from Yale University: Origins and immunotherapy of macroglobulinemia.

IWMF-LLS Strategic Research, cont. on page 7



Dr. Christian Buske, Dr. Jan Münch, and Dr. Daniel Sauter from Ulm University in Ulm, Germany: Characterization of endogenous CXCR4 inhibitory peptides to target WM.

Dr. Marcel Spaargaren from Academic Medical Center in Amsterdam, the Netherlands: Towards a rational targeted therapy for WM by kinome-centered loss-of-adhesion and synthetic lethality screens.

In total, the IWMF Board committed nearly \$1.7 million dollars spread over two years. Member donations made this commitment possible. Remember that 100% of all donations designated for the Research Fund go to research. Not a single penny goes anywhere else.

3. The Future

Following the success of the Strategic Research Roadmap to date, we will take three additional actions.

1. At its August meeting, the IWMF Board of Trustees will vote on creating a second RFP. This 2016 RFP will be issued in November with a proposal due date in February 2017. Based upon currently available funds, we would anticipate funding at least two new projects in June 2017. If we have more research dollars available, we will fund more projects.
2. Given the importance of the meeting, the name of the meeting will be changed to the IWMF-LLS Strategic Research Roadmap Summit. The 2017 IWMF-LLS Strategic Research Roadmap Summit will take place in October of 2017 in New York City.
3. The Imagine a Cure Campaign has been extended until 2021, and its fundraising goal has been expanded to \$25,000,000. The extension and expansion are designed to help us fund as many research projects as possible. See page 20 for more details.

THE BING-NEEL JOURNEY OF JULIE DAVIDSON

AS TOLD TO ALICE RIGINOS, TORCH EDITOR



Julie and Wade Davidson visiting Greenfield Village in Dearborn, Michigan. The Village is part of The Henry Ford Museum.

An oncologist of 2016 informing a new patient of a diagnosis of Waldenstrom's macroglobulinemia will likely add the following phrases in rapid succession: "indolent cancer," "incurable but treatable," "watch and wait status possible for several, or even many, years," "many new drugs in preparation and trial," "patients may survive for decades." The newly diagnosed patient will likely not hear from his or her oncologist the words "transformation" or "Bing-Neel," referring to developments seen rarely in WM patients and, when seen, often following years of treatment. In this very personal account, written for publication in the Torch, WM patient Julie Davidson furnishes information in a frank and open manner about her experience as a patient diagnosed with Bing-Neel, the form of WM in which WM cells move into the patient's central nervous system.

About Bing-Neel we patients hear very little, in part because it is so rare, in part because it manifests itself in ways that are almost unique in each patient, and in part because most Bing-Neel patients of record do not live for more than 2 years following this second diagnosis related to WM.

Julie Davidson's experience as a Bing-Neel patient is here discussed in detail. This is a topic not found in the general literature and one that is referred to only infrequently in the personal reports we read in IWMF-Talk. Julie's brave voice is that of a survivor. She has been diagnosed with Bing-Neel, treated with powerful chemotherapeutic drugs, and at her most recent evaluation by her Dana-Farber team in May 2016 she received a report of results that were truly exciting because they showed a significant response to treatment in the reduction of involvement of her spinal nerves. Three and

a half years after learning of her Bing-Neel status, Julie is receiving hopeful signs of continuing survival.

Julie's personal message to others with a Bing-Neel diagnosis is one of encouragement and hope. In speaking openly, however, she acknowledges the feelings of loneliness and isolation that come with every diagnosis of cancer, especially when the cancer is a type that is so poorly understood. She is very clear that support from her family and a close WM friend (see the post script to this article) have enabled her to keep moving forward on her journey.

Loneliness and isolation are the words that Julie Davidson says best express the emotions she has often felt during her journey as a cancer patient. The same sentiment she hears repeated over and over when members new to IWMF-Talk express their relief in finding other Wallies who understand the

emotions they are experiencing as cancer patients. Loneliness and isolation are frequently cited, especially by the newly diagnosed, when persons intending to offer help and support make comments that are not so helpful and are often hurtful, or when the friends who initially offered a huge swell of support later begin to fade away.

From the outset, Julie's experience of the past 5 years was unusual, beginning as it did at age 55 with simultaneous diagnoses of both Stage III A breast cancer and the orphan blood disease we know as Waldenstrom's macroglobulinemia. Overnight she found herself to be a cancer patient with two very serious and very different forms of cancer. One can appreciate that a sense of isolation and loneliness enveloped her as she faced the decision of not only "how or when to treat" but "which to treat."

Aggressive treatment for the breast cancer followed for the next 10 months, treatment that seemed to also hold the WM in check, and then Julie found herself in new and lonely territory when she learned that, within 6 months of completing treatment for breast cancer, her blood disease had progressed from Waldenstrom's to Bing-Neel Syndrome (BN). In other words, already coping with WM, a rare disease, she was suddenly confronting that extremely rare form of WM occurring when the lymphoplasmacytic cells advance into the central nervous system (CNS).

Julie today speaks of her life before cancer diagnosis as a satisfying time marked by many accomplishments. Julie

The Bing-Neel Journey, cont. on page 9

and her husband of 38 years, Dr. Wade Davidson, met at the University of Tennessee Center for the Health Sciences in Memphis when Julie was enrolled at the School of Nursing and Wade was in training for his future career as an obstetrician-gynecologist. Today he remains a busy OB/GYN in the Nashville area where they reside. At the time of Julie's diagnosis in February of 2011, the Davidsons' two adult children were living independently, and Julie had moved on from a career in nursing to employment as a commercial property manager supervising properties in five states, a responsibility that required frequent travel for onsite visits. She had a busy life. She was up to its challenges.

Beginning August 2010, a sudden onset of severe headaches and progressively severe fatigue sent her on a round of consultations, first with a neurologist, then a second neurologist, followed by a rheumatologist, and, finally, a hematologist-oncologist for evaluation for possible MGUS on February 14, 2011 (not exactly a Happy Valentine's Day). The outcome was an overwhelming double diagnosis: Julie was told she had Waldenstrom's macroglobulinemia with an IgM of 1,600 and, during the course of the initial evaluation, the discovery of a suspicious axillary lymph node led to a diagnosis of two different types of Stage III A cancer in the left breast. Given that she had had a negative mammogram the previous June, Julie and her local medical team agreed to first address the breast cancer in order to try to prevent a recurrence. Her local oncologist remarked: "The WM won't kill you, but the search for it likely saved your life from a very aggressive breast cancer."

Chemotherapy began in March 2011 with the drug combination known as AC/TH (doxorubicin and cyclophosphamide, paclitaxel and Herceptin), followed by a double mastectomy in September and then by radiation therapy from November to December. Treatment for Julie's breast cancer was completed in December of 2011, 10 months after diagnosis. The chemotherapy also had a positive impact on her WM, cutting her IgM by over 50%.

This good news was, unfortunately, of short duration. Julie experienced a slow, but steady, improvement from the after-effects of the rigorous breast cancer treatment until a sudden, major drop in energy 6 months after the end of the radiation therapy. By now she and her husband were members of the IWmf and familiar with information about the disease posted on the IWmf website and on IWmf-Talk. Suspecting that Julie's situation was more complex than had been recognized by the local oncologist, Julie and Wade determined that the time had come to seek a second opinion and consult with a specialist in WM. They made the first of an on-going series of appointments with Dr. Steven Treon at the Dana-Farber Cancer Institute (DFCI) in Boston. At the time of their first visit, Dr. Treon reviewed Julie's medical record and shared their suspicion that "something else was happening." Suspecting the presence of Bing-Neel, he ordered a lumbar

puncture and an MRI. The results confirmed that WM cells were in the fluid of Julie's central nervous system. Julie returned to Boston within a few weeks to follow up with Dr. Mikael Rinne, a neuro-oncologist at DFCI with experience treating Bing-Neel patients.

Julie's new diagnosis, Bing-Neel Syndrome (BN), indicates the progression of WM into the central nervous system occurring in one of two forms, diffuse BN and tumoral BN. More specifically, Julie was told that she exhibited "Diffuse Leptomeningeal Bing-Neel with nerve root involvement" because WM cells were present in the cerebrospinal fluid within the meninges, the layers of protective tissue that enclose and protect the spinal cord and the brain. Further, the nerve roots in the caudal equina at the base of the spinal column were affected, as seen in the MRI, causing nerve pain and sensory-motor deficiencies in the lower extremities. These were among the symptoms eventually leading her to seek the second opinion.

Only 6 months after completion of the arduous treatment for breast cancer, Julie learned that her new diagnosis was that of a form of WM not merely rare (her local oncologist had never even heard of it) but one occurring in so many different manifestations that each case is virtually unique. No standard treatment has been determined for Bing-Neel. Most Wallies devote time to researching and learning about our very unusual lymphoma. Doing so with Bing-Neel can be a very scary experience. Not only is there very little information available, but also the publications that do provide information indicate a poor prognosis. As will be seen in Julie's case, however, this is not necessarily true.

Nonetheless, the new diagnosis was a crushing blow. Treatment recommended by the doctors at DFCI was aggressive and harsh: 11 rounds of high-dose methotrexate (MTX) administered intravenously over 6 months, from August 2012 to January 2013. The twelfth round was aborted due to rapidly worsening fatigue.

Describing this treatment Julie has written:

"MTX does involve a hospital stay. Mine were 5 days for each round. I was able to get treatment in Nashville as directed by Drs. Treon and Rinne. Sodium bicarbonate was given by IV for the first day to create a very alkaline blood and urine pH balance. Once a pH of 8.0 was reached, the MTX was given. This was followed 24 hours later by a "rescue" drug called Leucovorin to replace folate in the blood. Urine was monitored every 4 hours during the stay and blood every 12 hours. All of this mainly aimed at minimizing kidney damage. I could go home once the MTX urine levels had dropped to an acceptable level, which usually took 3 days.

I did experience nausea that was well controlled by medication and the ever-present fatigue, but did pretty well otherwise. The worst problem with MTX was boredom while in the hospital. I also developed a strong aversion to hospital food.”

By October of 2013, Julie’s WM had become quite active as seen in a rise of IgM level to 1,900, a drop in hemoglobin to 9, worsening fatigue, and the appearance of bulky adenopathy. Moreover, a lytic lesion was now recognized in her jaw, as well as a lesion on one kidney, which, thankfully, was not renal cell cancer. As Julie put it, “It is hard to imagine being thrilled that a tumor is ‘only WM’!”

The next treatment proposed by the DFCI doctors, in conjunction with her local oncologist, was a combination of fludarabine and Rituxan (FR) administered intravenously. In addition to treating the WM, intravenous FR had previously shown some success with other Bing-Neel patients in crossing the so-called blood-brain barrier to reach the central nervous system. The FR combination was administered to Julie from the end of 2013 until May of 2014. Once more the results included a drop in IgM (now to 700), as well as a rise in hemoglobin to 12.4, and a significant reduction of the lymphadenopathy. However, there were no improvements in the lytic lesion and the lesion on the kidney. Fludarabine was now discontinued, but Rituxan was administered as maintenance for one more year and then stopped when a low level of IgG became problematic.

By the time of Julie’s return visit to DFCI in the summer of 2015, however, her evaluation showed some welcome effects of the FR treatment in an IgM level of 205 and a slightly improved hemoglobin level of 12.9. Additionally, the IgH PCR level (used as another gauge to measure the Bing-Neel activity in the spinal fluid) became undetectable. This had not previously happened, even after the high-dose MTX eradicated the lymphoma cells in the spinal fluid. Julie did not return to DFCI for evaluation until May 2016.

Her most recent round of tests were a year later in 2016 and showed results that were exciting, yet very unexpected, not only to Julie and her husband, but also to the DFCI doctors who had monitored her care since the first visit. Surprisingly, the MRI showed signs of significant reduction of the spinal nerve root involvement caused by Bing-Neel. The amazed specialists quizzed Julie as to what she had tried “that was different,” and the only suggestion that she could offer was that she had tried acupuncture and “other Chinese medicine techniques.” Julie, it should be noted, tried these techniques at the suggestion of her other doctors in an attempt to counter spinal nerve pain caused by the Bing-Neel. She had at that time reached the very upper limits of the medications used to treat her increasing neuropathic pain. She has been told that there is no way to predict if, (and if so, when) the BN-related nerve pain might begin to dissipate.

And so this lonely journey of Julie Davidson into the unknown terrain of Bing-Neel – more than 3 years after finishing methotrexate, 2 years after finishing a combination of fludarabine and Rituxan, and 1 year after completing maintenance Rituxan – has taken another unexpected turn, this time for the better. Her neurologist at DFCI cautions, however, that it is unlikely that her central nervous system is altogether clear of the cancer cells. None of the consulted experts can chart the next turn in the road for Julie or when it will come.

When she speaks of having faced so much alone over the past 5 plus years, Julie is quick to add that there is a hero in this story, one who has been unflinching in his support. Her hero is her husband, her companion at every critical turn, sharing the disappointment of bad news and the bursts of hope coming with good news. At the beginning of this difficult road, Wade told Julie that her job was to find ways to reduce her stress and use that energy to fight the cancer battle and that his job was to take care of her. Wade not only accompanies her on visits to the experts but also has taken on many household chores, including shopping and even preparing dinner after long and busy days at his “real job” for most of the last 5 years.

The pace of life today for Julie is far from the frantic schedule she kept before diagnosis, when her employment kept her on the run and her family said she worked “way too hard.” In fact, she lost her job early on in her personal saga. She now drives, runs small errands, and can cook 3-4 times a week, but she is unable to negotiate large grocery and retail stores. Her level of fatigue can be crippling, and she spends much time resting. Nonetheless she walks the dog roughly 1 mile a day and participates in a cardiac rehab type program 3 days a week where she works under the supervision of an exercise physiologist. However, even minor increases in time, reps, or resistance can cause major energy set backs or muscle weakness. Normally, she will have a few good days followed by a couple of days of debilitating fatigue. For the nerve pain in the left hip and thigh, the lower right side from the hip to the foot, and intercostal neuralgia, she sees a pain physician and her acupuncturist. Another “job” Wade asked her to do from the beginning was to challenge her mind, to help minimize “chemobrain,” by playing computer games. She has mastered those skills!! But, unfortunately, she still has significant chemobrain.

Looking back over the past 5 years, Julie adds the following observations. Each new cancer diagnosis brought on a flood of emotion. Each time the “alone again feeling” surfaced as those around her tried to understand the personal challenge of cancer but really could not. Friends continued to drift away. It seemed each new doctor’s appointment brought more bad news. After a while, she found that she had run out of tears. She became numb. Her response became “OK, we have a problem. What are we going to do about it?” Her

doctors have been amazed at Julie's ability to deal so well with adversity. She has borrowed her motto from the movie *Finding Nemo*: "Just keep swimming, just keep swimming." Despite the fatigue, nerve pain, and other challenges, she says that every day she puts her feet on the floor is a good day. Currently, everything is in remission, much to the surprise of her doctors, as noted above.

In spite of the mark that Bing-Neel has left upon her life, it is clear that Julie is not defeated. She has been challenged by her disease and has risen to the challenge of learning all she can about it so that she may live better with it. She is now eager to help others feeling "all alone with Bing-Neel" and has assumed the role of active volunteer for the IWmf. Her name appears on the LIFELINE List as an experienced patient willing and ready to speak about the emotions and challenges of WM and BN and offer some information based on her own experience concerning diagnosis, treatment regimens, details about specific drugs. Her offer comes with "a broad shoulder, an ability to listen and support others," when she writes:

"I am now listed as the resource person for BN on the IWmf support persons list. I am on the same road with those facing a BN diagnosis and can speak to experience. I am available by phone, Skype, or FaceTime, if you would find it helpful."

Her email address is jeffdavidson@icloud.com and her cell phone number is 615-429-2017. She is quick to admit that she is sporadic with checking and responding to email. She asks your patience with email responses or welcomes phone calls for a more timely response.

By way of a post script to this article, Julie Davidson noted that the isolation brought on by the cancer diagnosis can be greatly diminished if one acquires a "cancer friend," one who

shares your diagnosis and with whom you feel free to speak frankly about any and all aspects of the cancer survivor's life. For Julie such a friendship developed with Grete Cooper through contact initiated via IWmf-Talk. Julie writes, "She and I 'found' each other on IWmf-Talk and have supported each other through good and bad for about 5 ½ years. I cherish the friendship and she has become my 'best friend.' We can tell each other anything and everything." Grete's response when Julie wrote that she is preparing an article for the *Torch* is an excellent conclusion to this article when she says of her friend Julie Davidson:

"I cannot think of anyone else with your kind of stamina and will to live and thrive. You'll be an encouragement to every *Torch* reader! Just a fleeting idea ... the article may be an excellent opportunity to say something about how important 'cancer friends' can be to each other. I don't know if you remember, but you once asked me if you could say something about it on IWmf-Talk. It's a very important topic and the two of us are proof that it's immensely helpful to have a 'travel companion' and Best Friend Forever. We have 'traveled' together for 5 ½ years ever since we were both diagnosed with WM."

Recommended for further information about Bing-Neel syndrome: a recent publication by Dr. Jorge Castillo, Dr. Steven Treon, and 13 other oncologists who have treated patients with Bing-Neel: Central nervous system involvement by Waldenström macroglobulinemia (Bing-Neel syndrome): a multi-institutional retrospective study. British Journal of Haematology 172.5 (March 2016) 709-715. This multicenter study combines the records of 34 patients to describe the characteristics of the disease plus the diagnostic criteria, range of response to therapy, and other data, including survival statistics.

MY IBRUTINIB STORY: SIX YEARS AND COUNTING

BY DAVID SELLERS, IWmf MEMBER

The autumn of 2001 was a challenging time in my life. As I was preparing to leave my Greenwich Village apartment for work on September 11 (my birthday), I saw the first news reports that a plane had hit the World Trade Center. By the time I arrived at work, the first tower had fallen. Soon after, the second tower also fell. My office closed, the subways closed, and I walked home with the millions of other shaken New Yorkers trying to make sense of the senseless. One month later, with the smell of the smoldering Trade Center still noticeable in the air, I was about to receive more bad news that was more personally devastating.

My physician had noticed a downward trend in my hemoglobin, and he sent me to be examined by a hematologist, just to be sure there was nothing seriously wrong. I had never had a serious illness, and I really did not think that was about to change as I went through various blood tests and a bone marrow biopsy. A couple of days after the biopsy I received a call from the hematologist with the bad news. Her diagnosis was multiple myeloma. I was stunned. A quick check online revealed the frightening facts about the disease, and I quickly went from stunned to devastated.

My Ibrutinib Story, cont. on page 12



David Sellers on a recent trip to Portugal. David credits ibrutinib for allowing him to travel and in other ways to return to a life that is close to his "old normal" – that is, life before WM.

The next day I received another call from the hematologist. She told me she had made a mistake and that I actually had a different disease, Waldenstrom's macroglobulinemia. Back online I went to learn about this unpronounceable affliction. The prognosis at that time was generally stated to be survival of 5-7 years from the time of diagnosis. Not great, I thought, but the more research I did, the more convinced I became that the statistics were outdated. Skip forward 15 years, and I'm still here thanks to new therapies that didn't exist when I was first diagnosed.

Not that it's been a cakewalk. I've had treatments that worked for a while (Cytosan), treatments that worked but were likely to cause serious side effects if I continued taking them

(Velcade), treatments that set off allergic reactions in my body (IVIg, Rituxan), and drugs that weakened my bones to a level near osteoporosis (prednisone). However, they did keep me alive until something more effective came along.

For most of the past decade, I've had the good fortune to be treated by Dr. Richard Furman at Weill Cornell Medical Center. He is a brilliant physician who has made every effort to treat my disease without the use of drugs that would further damage my bone marrow. So it was in 2010 when he asked if I would like to participate in a clinical trial of a new targeted therapy, a Bruton's tyrosine kinase (BTK) inhibitor then known as PCI-32765. Dr. Furman was very involved in the clinical development of this drug, which we now know as ibrutinib.

I jumped at the opportunity to enter this Phase I trial at Weill Cornell with Dr. Furman as Principal Investigator. This was the first trial for ibrutinib, and I was the first WM patient to receive it. This drug, which eventually earned FDA approval in January of 2015 for WM under the trade name of Imbruvica, turned out to be my miracle drug. It's no exaggeration to say that these little pills gave me my life back. I soon had the energy and motivation to do the things I enjoy, to travel, and to just live my life as I had before my diagnosis.

Over the past couple of years there have been indications that suggest ibrutinib is not working quite as well for me as it did for the first few years. There have been a few setbacks, including several hospitalizations for pneumonia, and my IgM has crept slowly upwards to a new plateau, although still far below what it was at the time I joined the trial. So we're trying something a little different. I'm now taking the commercial version of ibrutinib with a dosage of three pills each day, and Dr. Furman has added a five-week course of ofatumumab. We're hoping the ofa reduces the WM in my bone marrow and helps to boost the effectiveness of the ibrutinib. Fingers crossed. It's been a long twisting journey since October of 2001, but I'm doing reasonably well these days. And I'm still feeling optimistic.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Imbruvica Rejected in the United Kingdom for Cost Reasons – Imbruvica (ibrutinib) has been rejected by the United Kingdom's cost agency, the National Institute for Health and Care Excellence (NICE). The decision was based on the agency's conclusion that the drug failed to represent an effective use of resources. At the time of this announcement, Imbruvica was priced at 55,954.50 pounds (\$78,000 US) for annual treatment and is sold to the National Health Service by Johnson & Johnson's unit, Janssen, at a significant discount. This decision is currently undergoing appeals by patient advocacy groups, including WMUK.

Gilead Sciences Halts Clinical Trials of Idelalisib (Zydelig) Because of Serious Adverse Events – The US Food and Drug Administration (FDA) has issued an alert that six clinical trials of idelalisib (Zydelig) in combination with other therapies have been halted by Gilead Sciences because of reports of an increased rate of serious adverse events, including death, mostly due to infections. The halted studies were exploring idelalisib in chronic lymphocytic leukemia, small lymphocytic lymphoma, and indolent non-Hodgkin's lymphomas. The FDA announcement follows a similar decision from the European

Medical News Roundup, cont. on page 13

Medicines Agency (EMA), which placed idelalisib under a safety review. At press time, a review committee of the EMA concluded that the benefits of idelalisib outweigh the risks, but the EMA has not yet issued its final position. Patients currently on the drug do not have to stop taking it; instead they should be closely monitored, and it is recommended that they receive prophylaxis to prevent *Pneumocystis* pneumonia and undergo monthly monitoring for cytomegalovirus during treatment and for up to 6 months afterward.

Phase I Trial Opens for Immunotherapy in Asymptomatic LPL Patients – MD Anderson Cancer Center is opening a Phase I trial utilizing immunotherapy for asymptomatic patients with lymphoplasmacytic lymphoma (LPL), including WM. The therapy is a DNA vaccine encoding antigen specific to each patient's particular tumor cells and will be administered to determine the maximum tolerated dose and safety profile. The clinical trial identifier number on *clinicaltrials.gov* is NCT01209871.

Ibrutinib May Be Effective in Treatment of Bing-Neel Syndrome – In correspondence to the *British Journal of Haematology* from the Bing Center for WM at Dana-Farber Cancer Institute, it was suggested that ibrutinib is able to cross the blood-brain barrier to treat Bing-Neel syndrome (BN), a rare complication of WM in which the WM cells infiltrate the central nervous system, with or without the presence of IgM in the cerebrospinal fluid. The letter reported the case of one patient diagnosed with WM in 2009 and BN in 2011, who progressed despite treatment with methotrexate, rituximab, and bendamustine. The patient tested positive for the MYD88 L265P mutation but had wild-type (unmutated) CXCR4. In 2014, he began treatment with a higher-than-usual dose of ibrutinib (560 mg daily). After 3 months of therapy, his hemoglobin increased, his IgM decreased, and PET and MRI scans of the brain showed improvement. Ibrutinib and its active metabolite were detected in his cerebrospinal fluid. The patient continues to do well in partial remission and remains on ibrutinib at 23 months. The authors suggest that optimal dose and scheduling of ibrutinib in BN remain to be clarified.

New Formulation of Bendamustine Is Approved by FDA – Teva Pharmaceuticals and Eagle Pharmaceuticals announced that the US Food and Drug Administration (FDA) has approved Bendeka, a low-volume, short-time (10-minute) formulation of bendamustine hydrochloride. Teva has discontinued production of its Treanda formulation of the same drug.

Phase I Study Will Look at New Bispecific Monoclonal Antibody Treatment for CD20+ B-Cell Malignancies – The Weill Cornell Lymphoma Program recently opened a new Phase I research study of REGN1979 in patients with CD20+ B-cell malignancies previously treated with CD20-directed monoclonal antibody therapy, such as rituximab. REGN1979 is a bispecific (anti-CD20 and anti-CD3) monoclonal antibody

with a mechanism of action different from that of other anti-CD20 antibodies. REGN1979 will be administered as an IV infusion, weekly for the first four weeks, then monthly for five months, for a total of nine doses over six months. After completing treatment, trial participants will have follow-up visits monthly for six months. This clinical trial expects to enroll 150 patients, and the trial identifier number on *clinicaltrials.gov* is NCT02290951.

First Patient Dosed in Study of New Antibody Drug Conjugate Targeting CD19 on B-Cells – ADC Therapeutics announced that the first patient has been dosed in a Phase I trial to evaluate its antibody drug conjugate ADCT-402 in relapsed/refractory B-cell non-Hodgkin's lymphoma. The two-stage trial will evaluate the tolerability, safety, and activity of ADCT-402, with the first stage a dose escalation study of 30 patients at ten clinical sites across the US and the European Union. ADCT-402 combines a humanized monoclonal antibody targeting the CD19 surface protein expressed on B-cells and a pyrrolo-benzodiazepine "warhead" that is toxic to the B-cells. The clinical trial identifier number on *clinicaltrials.gov* is NCT02669017.

Trial Reports Results of Subcutaneous vs. Intravenous Administration of Rituximab in CLL – A multicenter trial reported in the March 2016 issue of *The Lancet Haematology* on the results of subcutaneously administered rituximab vs intravenous rituximab. This Phase Ib study of 176 previously untreated patients with chronic lymphocytic leukemia was performed at centers in Europe, North America, South America, and Australasia. Patients received either 1600 mg of subcutaneous rituximab or 500 mg/m² of intravenous rituximab plus fludarabine and cyclophosphamide every 4 weeks for up to six cycles. Patients given subcutaneous rituximab achieved serum concentrations that were similar to those achieved with intravenous rituximab, with a similar safety and efficacy profile between the two groups. More patients reported skin reactions with subcutaneous rituximab, but these were primarily of low-grade severity.

FDA Approves Venetoclax for Patients with Relapsed CLL – The US Food and Drug Administration (FDA) has now approved venetoclax (Venclexta) for patients with chronic lymphocytic leukemia (CLL) who have a 17p chromosome deletion and have failed at least one prior therapy. The approval was based on a Phase II trial in which CLL patients with the deletion achieved a 79.4% overall response rate to oral venetoclax. Patients received Venclexta once daily with a weekly dose ramp-up schedule (20, 50, 100, 200, 400 mg) over a period of five weeks with prophylaxis for tumor lysis syndrome. Patients were then dosed daily with 400 mg until disease progression or discontinuation. Ninety-six percent of 103 evaluable patients experienced an adverse event of any grade, including 76% with grade 3-4 (moderate to severe) events. The most common adverse

events included neutropenia (43%), diarrhea (29%), and nausea (29%). Infections occurred in a total of 77 patients (72%). Venetoclax is a BCL-2 inhibitor.

EMA Recommends Second-Generation BTK Inhibitor Acalabrutinib for Orphan Drug Status in Treatment of LPL and Other Lymphomas – AstraZeneca announced that the European Medicines Agency (EMA) has recommended acalabrutinib (ACP-196) for orphan drug status for the treatment of lymphoplasmacytic lymphoma (LPL), chronic lymphocytic leukemia, small lymphocytic lymphoma, and mantle cell lymphoma. Acalabrutinib is a second-generation Bruton's tyrosine kinase (BTK) inhibitor in the same class as Imbruvica (ibrutinib), but with reportedly fewer side effects and potentially better efficacy. Orphan drug status is awarded to medicines promising significant benefit in the treatment of rare, life-threatening diseases, and the designation provides companies with special development and market incentives. AstraZeneca recently bought control of Acerta Pharma in order to acquire acalabrutinib.

Another Second-Generation BTK Inhibitor Begins Phase Ia Trial in Belgium – Yet another second-generation BTK inhibitor called SNS-062 has begun a Phase Ia trial in Belgium to evaluate its safety profile in healthy subjects. The trial is expected to enroll 52 subjects and will assess a range of doses, as well as the effects of food and interactions with CYP3A4 inhibitors on the activity of the drug. The drug maker, Sunesis Pharmaceuticals, intends to use the treatment for B-cell malignancies in Phase Ib/Phase II studies and hopes that SNS-062 has the potential to address emerging resistance to currently marketed BTK inhibitors.

FDA Approves Gazyva in Treatments for Follicular Lymphoma Patients Who Fail Rituxan Regimens – The US Food and Drug Administration (FDA) has approved Gazyva (obinutuzumab) plus bendamustine followed by Gazyva alone as a new treatment for follicular lymphoma patients who do not respond to a Rituxan-containing regimen or whose follicular lymphoma returned after treatment with such a regimen. The approval was based on a Phase III GADOLIN study, in which this regimen demonstrated a 52% reduction in the risk of disease worsening or death, compared to bendamustine only. The most common Grade 3-4 (moderate to severe) side effects were low white blood cell counts, infusion reactions, and low platelet counts. Gazyva in combination with chlorambucil has also been approved in the US for people with previously untreated chronic lymphocytic leukemia. Gazyva is a third-generation, fully humanized anti-CD20 antibody manufactured by Genentech.

Phase III Study Suggests Gazyva-Based Treatments Improve Progression-Free Survival Over Rituxan-Based Treatments in Previously Untreated Follicular Lymphoma – In other Gazyva news, a Phase III study of people with previously untreated follicular lymphoma looked at Gazyva plus chemotherapy followed by Gazyva alone for up to

two years in a head-to-head comparison with Rituxan plus chemotherapy followed by Rituxan alone for up to two years. Results of an interim analysis of this Phase III GALLIUM trial showed that Gazyva-based treatment significantly increased progression-free survival. The study is being conducted in cooperation with the German Low Grade Lymphoma Study Group, the East German Study Group Hematology and Oncology, and the National Cancer Research Institute in the UK. Additional combination studies investigating Gazyva with other approved or investigational medicines, including cancer immunotherapies and small molecule inhibitors, are planned or underway across a range of blood cancers.

Severity of Peripheral Neuropathy in Multiple Myeloma Patients Treated with Bortezomib Is Associated with Low Vitamin D Levels – An article in the February 2016 issue of the journal *Supportive Care in Cancer* concluded that the severity of peripheral neuropathy is associated with lower vitamin D levels in multiple myeloma patients who have been treated with bortezomib (Velcade) and/or thalidomide. In this study, researchers enrolled 111 multiple myeloma patients, who underwent physical examinations and neurologic assessments and completed self-assessment questionnaires. Results showed that 42% of patients were considered to have either deficient or insufficient vitamin D levels; those patients with levels less than 20 ng/mL were more likely to have severe peripheral neuropathy, including both motor and sensory types.

Trial Reports Results for Oral HDAC Inhibitor in Relapsed/Refractory Lymphoma – A Phase I/II multicenter study of the oral histone deacetylase inhibitor abexinostat in relapsed/refractory lymphoma was reported in the journal *Clinical Cancer Research*. The recommended Phase II dosing was 45 mg/m² twice daily, 7 days/week given every other week. The overall response rate was 64.3% in follicular lymphoma patients and 27.3% in mantle cell lymphoma patients. Moderate to severe adverse events included thrombocytopenia (low platelets), fatigue, and neutropenia (low neutrophils).

EMA Grants Orphan Drug Status for Monoclonal Antibody Treatment of Autoimmune Hemolytic Anemia – True North Therapeutics announced that the European Medicines Agency (EMA) has granted orphan drug status for TNT009 for the treatment of autoimmune hemolytic anemia, including cold agglutinin disease (CAD), in which autoantibodies target and destroy red blood cells. CAD is a condition found in a small proportion of WM patients. TNT009 is a monoclonal antibody that selectively inhibits the classical complement pathway of the immune system by targeting C1s, a protein in the pathway.

Phase I Study Includes WM Patients in Testing of Oral TORC1/2 Inhibitor – A Phase I dose escalation study looked at the oral TORC1/2 inhibitor called TAK-228 (formerly

MLN0128) in patients with relapsed or refractory WM, multiple myeloma, and other non-Hodgkin's lymphomas. Thirty-nine patients (4 with WM) received TAK-228 at various strengths and dosage schedules. The most common moderate to severe toxicities were thrombocytopenia (low platelets), fatigue, and neutropenia (low neutrophils). One WM patient achieved a partial response, one WM patient achieved a minor response, and 2 WM patients had stable disease.

Phase III Trial Compares Maintenance Rituximab vs Rituximab Retreatment Strategy in Small Lymphocytic Lymphoma and Marginal Zone Lymphoma – As part of the Phase III RESORT trial comparing maintenance rituximab vs rituximab retreatment in patients with asymptomatic, low tumor burden indolent lymphoma, a sub-study compared the two strategies for small lymphocytic lymphoma and marginal zone lymphoma. Patients responding to rituximab treatment

weekly x 4 were randomized to either 1. maintenance rituximab (single dose every 3 months until treatment failure) or 2. rituximab retreatment (rituximab weekly x 4) at the time of each progression until treatment failure. At a median of 4.3 years from randomization, treatment failure occurred in 18/23 patients with rituximab retreatment and in 15/29 patients with maintenance rituximab. The median time to treatment failure was 1.4 years for rituximab retreatment and 4.8 years for maintenance rituximab. Survival did not differ. This trial was conducted by the Eastern Cooperative Oncology Group and was published in the *British Journal of Haematology*.

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

FIRST-TIMER FROM DOWN UNDER AT THE ED FORUM

BY ANTHONY STEELE, DIRECTOR OF SUPPORT SERVICES
THE LEUKAEMIA FOUNDATION. AUSTRALIA



*Anthony Steele, Director of
Support Services, the
Leukemia Foundation, Australia*

In Australia – a country similar in size to the US – around 150 people are diagnosed with Waldenström's macroglobulinaemia (WM) each year. This makes it very difficult for those affected by WM 'Down Under' as they are often separated by large distances and feel isolated. In a former role of mine, working clinically as a nurse in a leading Brisbane hematology/oncology unit, I knew of only a few people with this diagnosis. WM was on my radar, but barely.

Now, as the national Head of Blood Cancer Support for the Leukaemia Foundation (Australia), I have had the good fortune to meet a dedicated group of people affected by WM, called the WMozzies. This Australian patient support group has ensured WM is on my radar and has heightened my understanding of the great and unmet needs of all those with this diagnosis. WMozzies offered me the opportunity to attend the IWMMF Educational Forum in Providence, Rhode Island, this past June – my very first WM workshop!

For several years, I have received the IWMMF *Torch*. It is always an impressive publication, and it made me aware of

the work of this organisation. Even so, I did some homework on the IWMMF and also knew two colleagues who had attended an IWMMF Ed Forum in the past. I asked many questions about what to expect and was amazed at their positive responses. I began to really look forward to attending and to meeting the amazing volunteers who are the IWMMF.

I flew 25 hours, crossed international date lines, the equator, the Pacific Ocean, and the breadth of the US to get to Providence, arriving the night before the workshop commenced. I had changed time zones and seasons and then faced traffic approaching on the opposite side of the road. Although slightly dazed, nothing could reduce my enthusiasm for the three days that followed.

The 2016 IWMMF Educational Forum began with an introductory session for Forum first-timers. I had already been met by the amazing IWMMF team and instantly felt at home. It was reassuring to know that I would be in a room full of other first-timers; all in the same situation of not knowing what to expect and looking forward to a session aimed specifically at us.

When I entered the conference room, I was surprised at just how many attendees there were! For a rare condition, this seemed a huge crowd of people—all wanting to find out more about their disease. I was so impressed that this group of people had a place to go to learn more about their condition directly from the world's best WM clinicians and researchers, to feel supported, to learn a new health language, to share experiences, and, importantly, to feel less alone with this condition.

First-Timer from Down Under, cont. on page 16

This initial session was an excellent introduction to the themes and language that would be used throughout the workshop and eased participants into the rest of the program. I learned many things in this session. For example, I was astonished that around 20% of the audience had other family members with WM or another blood cancer. What also was affirmed to me was that no two people with WM have the same disease experience; WM is truly a diverse disorder.

The Forum's speakers explained some complex themes in language that was easy to understand, and I was very impressed with their candor when discussing how they treat patients. They emphasized how they consider the patient experience as much as a patient's test results when deciding on how and when to treat. Treatment decisions often are determined by how the patient is feeling! During discussions, it became apparent the reason for this is that some people can have a test result where they feel good, while others with the same test result may feel terrible. How people are affected is quite individual, therefore treatment needs to be individual, too.

At the end of this session, the first-timers had the opportunity to put questions to the speakers. This meant all the "things" that played on the minds of these people with WM could now be explored in a safe place. Interestingly, the types of questions asked then were very different from those asked in subsequent sessions, when more technical and specific questions were put forward. To me, this confirmed the importance of having a first-timers' session aimed at people still coming to terms with so many complex topics, language, and coping strategies.

Following this initial session, the other Forum participants joined us and, again, I was astounded as the conference room filled with more than 300 participants. Extra seats were required to accommodate everyone who had travelled from near and far to learn more about their WM – or how to care for a loved one with this rare disease.

We were then introduced to the four pillars of the IWMF Strategic Research Roadmap that included:

- cell signaling
- 'omics'—genomics, epigenomics, etcetera
- immunology
- the bone marrow microenvironment.

It was great to hear of the very clear strategy IWMF has in its quest to beat this disease through focused research.

The first-timers session and the Research Roadmap talk set me up for the rest of the workshop. As topics became increasingly more in-depth, I had learned enough by then to follow each subsequent session, thereby gaining a deeper insight into WM, treatment options available and in development, and the IWMF's role.

I learned about survivorship issues and how people can live well with this disease. Also, that not every illness or symptom is related to WM, that normal ageing processes continue despite a WM diagnosis. I was really moved by a presentation from a person with WM and how she manages living with the disease despite the impact it has had on her life. Her generosity in sharing her personal journey enabled others to discuss their issues in a setting where they were truly understood and supported.

The Ed Forum program gave participants several opportunities to ask questions of the speakers, and the depth of knowledge many WMers had about their blood cancer was truly astounding. What an empowered group!

I made sure I met and talked with as many people as possible during the workshop. They were so friendly and welcoming, and I made many "Waldenfriends." I even had the opportunity to inform some of them that Sydney is not Australia's capital city!

I met many people from the US and beyond. Roger Brown, from the UK, was particularly inspiring with all of the work he is doing in his home country. I came away from the Forum with a broader knowledge of WM and the diversity of people it affects. I have a clear understanding of the IWMF and the amazing volunteers who run it. They are inspirational!

I'm hooked and look forward to having a more active role in supporting people with WM here in Australia, and I extend my thanks to the WMozzies who gave me the opportunity to attend the 2016 IWMF Educational Forum.

I would recommend attending an Ed Forum in the future to anyone who has, or loves someone with, WM. Reflecting on how the Forum was organized – by volunteers, and with all the speakers presenting in their own time and at no cost, I was reminded that it only came about due to the kind and generous donations of a small community of those affected by WM. Well done IWMF and the entire WM community. You are truly inspiring!

FROM IWmf-TALK

BY JACOB WEINTRAUB, MD

In June Secret Wally kept us informed and entertained during the annual IWmf Educational Forum, held this year in Providence, RI. Other attendees also reported on presentations of special interest and their experiences at the Forum. As usual, there was a stellar group of WM experts presenting on topics ranging from basic information about WM for first-timers to the very latest research in Waldenström's macroglobulinemia. The attendees represented a cross section similar to the IWmf-Talk participants in that they included all levels of experience with WM.

IWmf-Talk continued right through the Ed Forum and had continuing discussions of treatments, side effects of treatment, ongoing manifestations of our WM, and a multitude of postings of informational articles and relevant human-interest stories. Although I had intended to devote this column to topics other than Imbruvica/ibrutinib, the ongoing discussions of this oral medication continue on IWmf-Talk and present new information and raise new questions. With an increasing number of people starting on Imbruvica, it is important for all of us to keep up with the most current information. The Doctor on Call article by Dr. Jeffrey Matous (page 1 and following) is a good place to begin.

HUMAN INTEREST/ARTICLES

A multitude of interesting and helpful articles is posted regularly, and a full column could be done just using such links. Here are a few of the most relevant and interesting.

IWmf-Talk Manager and Trustee Peter DeNardis posted a link to an article in *Cure* magazine about a frequently discussed topic, cancer-related fatigue. The article covers multiple facets of fatigue in various cancer situations and has some suggestions on improving quality of life when one has fatigue:

<http://www.curetoday.com/community/mike-verano/2016/05/cancer-fatigue>

Another link from Pete is to an article with video of several individuals discussing the impact of their cancer. Sometimes it helps to know that you are not alone in the way you feel about having cancer. IWmf support groups fill this function in our lives, but this video is helpful, too. It is very emotional. <http://tinyurl.com/survivor-discuss>

Pete also posted a link to additional videos that people may find to be of comfort. These video interviews were taken at last year's Ed Forum and are more WM-specific:

<http://www.iwmf.com/publications/videos-about-iwmf>

Pete also posted a link to an exceptionally good item about what not to say to a cancer patient. All of us have had friends and relatives and colleagues try to comfort us with words of wisdom, often with the opposite results. This is a

list compiled by the folks at Roswell Park Cancer Institute based on comments from their Facebook page, definitely not a journal article.

www.roswellpark.org/cancertalk/201603/what-not-say-cancer-patient

Julie T responded to Peter's post. Looking back to the time her husband was treated for prostate cancer, Julie added that one comment she disliked the most was "let me know if I can do anything." She noted that it isn't that easy for a patient or caregiver to call and ask someone if they can do shopping or housework or other favor. Someone who wants to help should ask directly at a specific time, for example, to call and say "I'm headed to the store, can I get you anything?" or "I'm making soup, can I bring some over for you?" A person can also call and directly ask if the patient wants to go for a ride or out to lunch. All are very helpful suggestions.

IWmf Trustee Wanda Huskins posted several items. A favorite of mine is a link to an article titled "Argentine Tango 'Therapy' Helps Restore Balance for Cancer Patients with Neuropathy." This comes from The Ohio State University Comprehensive Cancer Center and notes the high frequency of neuropathy in cancer and chemo patients. The article explains that long-term neuropathy in the feet and toes can be especially problematic because of its effect on balance and gait. Patients who participated in sessions of Argentine Tango for 5 weeks had significant improvement in balance, and participants found this much more enjoyable than physical therapy.

<http://scienmag.com/argentine-tango-therapy-helps-restore-balance-for-cancer-patients-with-neuropathy>

Several members then posted that they were now looking for dance partners to try this activity.

Wanda also posted a link to an article titled "Reliving Agent Orange: What the Children of Vietnam Vets Have to Say." Although this may have limited general interest, Wanda felt this was important for those on IWmf-Talk who have been posting about this topic, and I agree. The subject even generated some discussion about a former IWmf-Talk member, **Jerry Fleming**, who lived in Texas and was instrumental in assisting many veterans obtain VA benefits based on exposure to Agent Orange.

<https://www.propublica.org/article/reliving-agent-orange-what-the-children-of-vietnam-vets-have-to-say>

Finally, Wanda posted a link to an article about the strong bond between cancer survivors, making it hard when we lose friends. It brought to mind IWmf friends who have left us, both recently and in the past.

<https://theguardian.com/commentisfree/2016/jun/23/cancer-survivors-bond-grief>

From IWmf-Talk, cont. on page 18

IMBRUVICA/IBRUTINIB

Problems with nails and skin are noted repeatedly.

Carol M reported that, although she has not been treated with Imbruvica, she has continuing problems with her nails. Her nails have white spots and splits, despite taking iron for anemia and using a topical treatment with strengthening polish.

Wanda posted a link to an article that indicated changes in hair and nails are a common issue with people taking Imbruvica.
<http://www.empr.com/news/hair-nail-abnormalities-common-with-cll-drug/article/483902/#>

Jan W reported she has been taking Imbruvica and has had thinning hair and brittle nails, but overall the treatment has restored her health. Her energy has improved and she is pleased with the result of treatment.

Ron T reported similar positive results from Imbruvica and also similar side effects including: brittle, ridged nails; deep skin cracks on his fingers, toes and heels; and muscle cramps. Overall, Ron considers these side effects to be minor compared to the benefits Imbruvica has provided.

Pavel I reported ongoing difficulty with splitting nails, which he finds to be not particularly problematic. However, Pavel warns that, if nailbed infection results, it can become a serious issue.

Paul L reported similar nail problems and also reported his strategy. He keeps his nails very short and uses a nail-hardening product, especially when the nails start splitting.

There also was some discussion about warts, which several people reported having. In the process of sequencing the genome of WM patients, the CXCR4 WHIM variant was discovered. After some research, **Pat G** reported that WHIM stands for “warts, hypogammaglobulinemia, infections, and myelokathexis,” as noted by Dr. Treon in at least one article. This suggests a reason for the appearance of warts on some of us.

Finally, a post from **Pete DeNardis** related to Bing-Neel Syndrome (BN) in which WM enters the central nervous system. This very uncommon complication of WM has been reported on IWMF-Talk (see also the article on pages 8-11 of this issue about the BN journey of one IWMF member). Pete quoted an article published in the form of a “correspondence”

providing information about one patient whose central nervous system disease was treated with ibrutinib/Imbruvica, demonstrating this medication’s ability to cross the blood brain barrier. This characteristic makes Imbruvica valuable in a medical setting that has not been previously reported.

BONE MARROW BIOPSY

This is another subject that appears periodically, especially as new members discuss their initial diagnosis and others discuss the need for repeat biopsy.

Davell H posed the question of whether she will need to have someone drive her home after the bone marrow biopsy (BMB) she would be having the next week. This will be done under local anesthetic only. She lives an hour from where the procedure will be done, so it will be an inconvenience for someone to come with her. Davell added that she had needed a driver with her Rituxan infusions when the premedication dose of Benadryl was increased.

Bonnie R posted that she has had 3 biopsies and was quite uncomfortable after each, so she wouldn’t want to drive.

Hank S reported that he has had multiple BMBs. He has been able to drive immediately after each of these, since only local anesthetic was used. Hank suggested that Bonnie request a chemical ice pack. Strapping one of those to the biopsy site works very well to reduce the intensity of soreness and helps to make any soreness go away more quickly. Hank only needed Tylenol for pain.

Pete S posted that his BMBs have been at Dana-Farber with the same nurse doing the procedure. She is very skilled and makes the procedure less uncomfortable. He drives 2 hours to get home, and it is no problem for him. He did have hip pain for a couple of weeks but thought it might have been all the work he was doing immediately afterward.

There were a number of posts commenting on the use of local anesthetic versus sedation or “twilight sleep,” as some called it. Some were fine with local anesthetic, others requested sedation due to anxiety over the procedure, and others requested sedation after having pain with an initial procedure.

Dr. Tom Hoffmann even commented that after his BMB, under local only, he went back to the operating room and performed 2 heart surgeries.

From IWMF-Talk, cont. on page 19

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

Pavel I noted that the problem with “twilight sleep” sedation is that, no matter how light it is, the hospital is legally obligated to make sure the person needs to be discharged with an escort.

A personal note from **Dr. Jacob Weintraub**, column editor: he has had two BMBs, one under local anesthetic and the other with sedation. To some extent the amount of pain with local sedation depends on the skill and experience of the person doing the procedure, and sedation is more likely to be done without any significant pain. However, an escort clearly is necessary with sedation or other pre-procedure medications that are likely to cause drowsiness. After a BMB under sedation, with samples drawn from both hips, he rode home the next day, 500 miles from Mayo Clinic to western Michigan, without significant discomfort.

DENTAL CONCERNS

Finally, discussions about dental problems followed reports by several members.

Joe B posted that he has had some uncommon dental issues for a few years now, diagnosed as external resorptive defect, which could be related to autoimmune disease. Joe’s dentist told him that he has three patients with external resorptive defect. Of the three, Joe and one other have had chemo, but the third patient has not. In Joe’s case the external resorptive defect has gotten into the root of one tooth, and he has had another tooth extracted.

Ann T also reported a problem with roots of her teeth found to be cracked or calcified. She saw an endodontist and

implant specialist before determining if she is a candidate for an implant.

Courtney P noted that her father was diagnosed in 2012 and has had dental extractions and a root canal in the last year. He seems to be in and out of the dental office every month. Since starting ibrutinib in August 2015, her father also seems to have an unquenchable thirst.

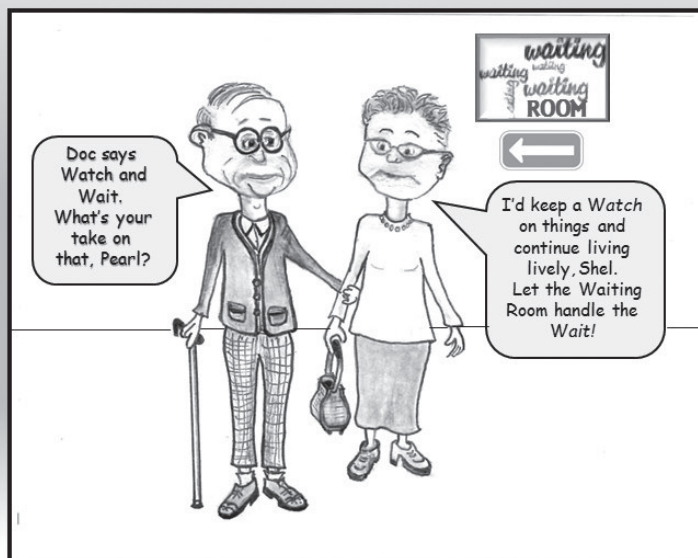
Susan P also reported dental issues since starting ibrutinib that included two root canals and decay in another molar. She does not have a problem with thirst but does have a dry mouth. Her dentist recommended Biotene mouth rinse and suggested that keeping oral tissue moist is essential to dental health.

Ron T reposted information from the WM Facebook closed group. This information was from Dr. Lisa Bozzetti, DDS. She suggested that there are a large number of medications that cause dry mouth and cavities, primarily due to losing the protective function of your saliva. Dr. Bozzetti added that most physicians do not consider the oral health consequences when prescribing these medicines. The list of medications includes lisinopril, Zocor, Norvasc, hydrochlorozide, Priolosec, Lasix.

Linda H reported she keeps on hand “Ice Chips,” a lozenge that comes in a tin and contains xylitol and is easier to use than some of the oral liquids.

As always, the list of topics discussed is too vast to include in any summary. You are all invited to join and participate, or even just to “lurk and learn,” from the wisdom and experiences of the other members.

Torch Toon by Linda Pochmerski



Watch and Wait refers to the time without treatment during which a patient is closely monitored by his or her physician. When treatment becomes necessary, patient and physician confer on the next step. Shel and Pearl are taking advantage of the W & W strategy by enjoying their true delight – demonstrating their nifty piece of footwork.

IMAGINE A CURE CAMPAIGN CELEBRATES SUCCESS

FROM THE FUNDRAISING COMMITTEE

The response from our members to the Imagine a Cure Campaign in support of vital member services and WM research has been amazing. We actually reached our original \$9,000,000 goal earlier than anticipated! To maintain this momentum, we announced with excitement at the Ed Forum in June that the Imagine a Cure Campaign is now extended for five more years. The new goal is \$25,000,000.

What happened since the start of the Campaign that encourages us to extend it and to set such an ambitious goal? What happened is that your response was very generous on the first call.

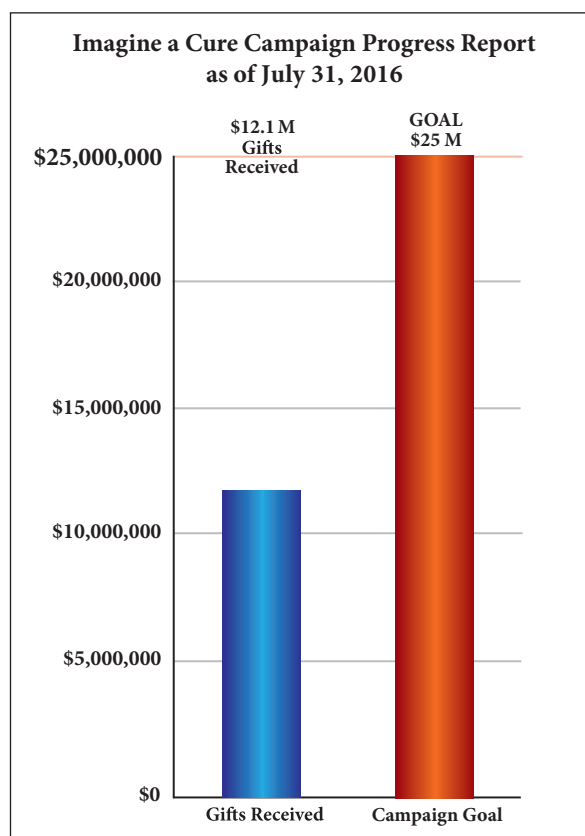
Because of your generosity, we were able to improve the services we provide to all those affected by WM. We have updated most of our educational booklets (provided to all of our members without charge), and new fact sheets have been developed that cover several major treatment options. To extend our international outreach, most of these have been translated into languages other than English.

We have updated our website, which is now translatable into 58 languages, to make it easier to navigate and access on mobile devices. We have created an international directory of WM experts who have agreed to provide consultations for patients as well as other physicians. When important news is published on the website, a news alert now goes out to our membership to better inform them about current developments.

We continue to improve the annual Ed Forum, our flagship event, to help both newly diagnosed and veteran WMers learn about the latest developments in the world of WM. We are now in the process of upgrading IWMF-Talk to improve the user experience. We have expanded our network of support groups, which now number 79, throughout the world. We have increased the scope of the very helpful LIFELINE that provides one-on-one information to WMers about treatments and other important topics from those who have had personal experience with them. And, of course, we continue to publish the very popular *Torch*.

All of these services are possible only because of the support we receive from members like you.

During the course of the Imagine a Cure Campaign, the IWMF has made commitments of almost \$5,000,000 to fund new research projects around the world. Clinical trials stemming from research advances partially funded by the IWMF led to FDA approval for ibrutinib, now also approved for use in Europe and in Canada. In May 2015 the IWMF partnered with the Leukemia & Lymphoma Society to bring together the best minds in WM research to create a new Strategic Research Roadmap that will allow us to continue the progress toward a cure. This meeting was so successful that those who attended agreed to meet yearly to update



the plan. We are fortunate to have some of the world's top medical researchers willing to spend their time searching for a cure for our disease.

It is now up to us to make sure the Research Roadmap is carried out through finding and funding promising new projects. Doing so will help us get to better treatments and a cure more quickly, but it will require that we double our research budget. This won't be easy, but we are committed to making it happen.

Because of the IWMF, WM patients are exceptionally well informed – not only about Waldenström's but also about the many research developments on the horizon. It is now time to concentrate on our research program. Let's be the patients who fund the research that leads to a cure for their disease.

Each year about one-third of our members donate to the IWMF. We have accomplished a lot with their help, but just imagine what would happen if everyone participated.

Please consider making a multi-year pledge to the Imagine a Cure Campaign today. Such pledges are vital to our ability to fund multi-year research projects. If you cannot make a pledge, please consider a current gift. And if that is not possible, please consider a legacy gift.

Your fellow WMers are counting on you.

Ed Forum Album 2016

Created by Alice Riginos and Sara McKinnie

With the theme of *Imagine a Cure: Pathways to Progress*, the 2016 IWMF Educational Forum took place in Providence, RI, over the weekend of June 10-12. The Forum was a spectacular success. Attendance exceeded 300 registered participants – the largest number in the 20-year history of the “Ed Forum” – who came to Providence with high hopes and expectations.

Attendees came to hear from fellow patients how one can live well with WM and to hear from the clinicians and medical experts about treatments presently available. They also came to learn how the highly specialized

researchers currently exploring the nature of our disease are advancing toward greater control of, and ultimately the cure of, Waldenstrom’s macroglobulinemia.

The 300+ registrants came to the right place to satisfy their hopes and expectations. The sessions at Ed Forum 2016 covered as many topics relating to WM as possible during the two and a half days of the Forum and demonstrated that we are truly following Pathways to Progress.

Many thanks to our photographers: Peter DeNardis, Wyatt Kostygan, and John Manusso

Thursday, June 9



By the middle of the day before the official start, the lobby of the Omni Hotel was bustling with IWMF volunteers. Board Members were ready for action. The registration area in the lobby was a scene of intense activity, while 28 enthusiastic Support Group Leaders and 2 Regional Contacts came through on their way to a buffet lunch and then to participate in a 6-hour Workshop under the leadership of Trustee Marcia Klepac.



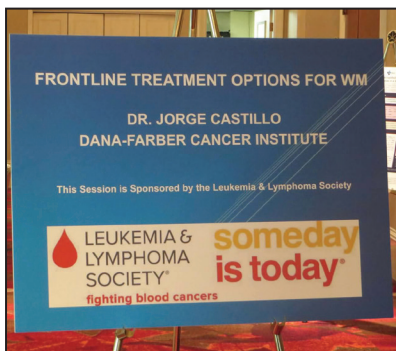
Friday, June 10



Every Ed Forum has its social side, and the 2016 Forum was no exception. The breakfast and luncheon buffets, the refreshment breaks, the Friday evening President's Reception and Welcome Dinner – all offered opportunities to socialize and make new friends. One overheard friends from past Forums greeting one another, immediately asking how they had fared over the past year. First-time attendees sat down at a table with strangers, but when they got up they were leaving a new circle of Waldenfriends.

A new event this year took place before the official opening of the Forum. A 'pre-session' was planned to provide a background for newly diagnosed patients and first-time attendees. Dr. Jeffrey Matous and Megan Anderson, NP-C, of the Colorado Blood Cancer Institute presented the basics as a team - clinician together with his nurse practitioner. They took time to explain, in layman's terms, the symptoms of WM, how it is diagnosed, and the most frequently used treatments. Their presentation was followed by the first ever "Ask the Veterans" Panel, where veteran WMers provided their insight and perspective in response to questions posed by those in attendance.

The 2016 Educational Forum formally opened at 10:30 am with words of welcome from the President. The first of many outstanding presentations delivered on Friday followed immediately. Dr. Stephen Ansell of the Mayo Clinic and IWMF Trustee began with a brief overview of WM and then outlined the four research priorities targeted by the LLS-IWMF Strategic Research Roadmap (see page 5 of this issue).



Friday afternoon's program continued with talks by two outstanding clinicians. Dr. Jorge Castillo covered frontline treatments while Dr. Matous returned to speak about treatments for relapsed patients. Lastly, Dr. Clare Humphreys spoke about 'chemobrain,' a topic that attracts much attention among treatment veterans.

For the balance of the afternoon, attendees were able to select from among several breakout sessions focused specifically on different forms of treatment, and caregivers were able to attend their own special breakout session.





Photographs on these pages capture moments from the 2016 Ed Forum, including presenters at the podium, breakout events, and social moments. As in years past, present in our midst was an anonymous and seemingly ubiquitous observer who signed with the pseudonym of Secret Wallie in his flashes from the Forum appearing on IWMF-Talk. On the pages below, selections set off by quotations are taken from Secret Wallie's posts. Thanks, Secret Wallie, for your heroic blogging on behalf of those who could not attend this year.

"Friday evening was the social highlight of the Ed Form, beginning with the President's Reception and followed by the Welcome Dinner. Carl Harrington provided a very upbeat Welcome Address (as he usually does!). Carl focused on the Imagine a Cure: Pathways to Progress theme and the IWMF Research Roadmap. He closed by encouraging all of us to support the IWMF Roadmap."

The entertainment of the evening, in the words of Wallie, was "a combination of personal story and original music by Ali Handal, accomplished singer/songwriter/guitarist and fellow WM patient. Interspersed between her songs were her viewpoints on life with WM, through diagnosis, treatment, and living with WM – all very compelling and true to the mark for many of us. Ali stood on stage, playing her acoustic guitar (hooked up to speakers), with no other accompaniment.

"At this point, brains overflowing with medical information and hearts filled with emotion from Ali's mini concert, attendees left the ballroom to relax and prepare for another full day of sessions."



Saturday, June 11



Dr. Karen Meneses

“The morning began with breakfast in the conference area,” wrote Wallie. “One could see new-found friends and old friends sitting together discussing the previous day’s presentations, their various symptoms, and just life in general!”

Saturday’s very full program opened with Dr. Maureen Hanley, a name familiar to all who follow IWMF-Talk, who spoke about WM and the eye. Dr. Edward Stadtmayer followed with a discussion of the current and future role of immunotherapy in treating WM patients. The final presenter of the morning was Dr. Karen Meneses on the topic of Cancer Survivorship.”

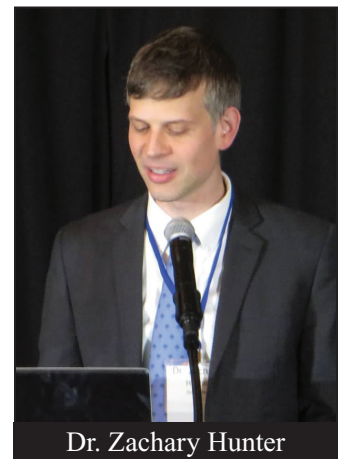
Sandwiched between the morning and afternoon presentations was lunch, of course, but there were also additional breakout sessions offered where attendees could choose from various topics focusing on different aspects of living with WM.

Genetics and genomics and their role in WM treatment were topics covered in the afternoon. Dr. Zachary Hunter led off with an explanation of the molecular basis of WM, while Dr. Ari Melnick turned the discussion to an explication of epigenomics. Dr. Steven Treon ended the day by outlining the ways that recent understanding of genetics and genomics has led to a proliferation of new treatment possibilities. These are fascinating and complex topics. You owe it to Drs. Hunter, Melnick, and Treon (and you owe it to yourself!) to view the videos of their presentations on the IWMF website and become familiar with the direction of current genomic research in WM.

During lunch members of the Board of Trustees reported to the membership on accomplishments of the past year and



Dr. Stephen Ansell

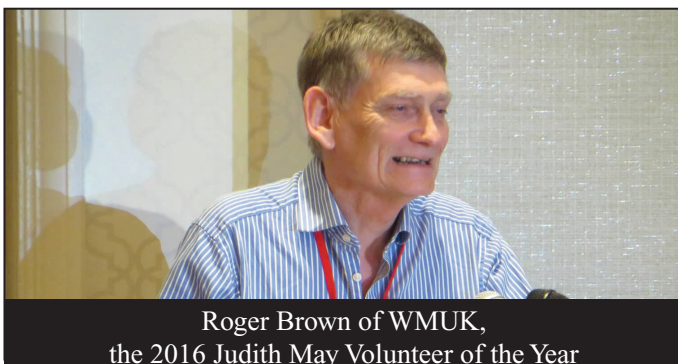


Dr. Zachary Hunter

plans for the future. Michael Sesnowitz, Vice President, Fundraising, announced that the Imagine a Cure Campaign goal was met before the deadline and that the IWMF is extending the campaign with a new goal of \$25,000,000 in order to fund the very important Research Roadmap initiative. The announcement was met with enthusiasm. “President Emerita Judith May then presented the IWMF Volunteer of the Year Award to a most deserving recipient. Roger Brown of WMUK has done tremendous work over the years to elevate the entire network of WMers in the UK to the point that it parallels the activities of the IWMF in the US – quite an accomplishment. His hard work and dedication go far and above what other “mere mortal” volunteers accomplish! Roger graciously accepted the award and downplayed his own accomplishments in his speech.”

Another highlight of the luncheon was the induction of new members for 2016 into the Ben Rude Heritage Society. Janice and Paul Rippas, Cordelia and Peter Stearns, and Elsa and Gary Bradley were present to receive their awards and were warmly thanked by Laurie Rude-Betts, Chair of the Society. All inductees have made provision in their estate plans for gifts to the IWMF.

The day ended with fellowship and exercise, with the opportunity for attendees to gather together for a walk through Providence, and dinner at locations of their own choosing with their old and new-found Waldenfriends.



Roger Brown of WMUK,
the 2016 Judith May Volunteer of the Year



Sunday morning provided another opportunity for “group exercise”, with a planned bike ride and a walk through downtown Providence.

When Dr. Morton Coleman of Weill Cornell Medical College rose to speak with the announced title ‘Global View of Indolent Lymphomas and WM,’ few could have predicted that his speech would, in the words of Secret Wallie, “be perhaps the most down-to-earth, engaging, and uplifting presentation of the weekend! Dr. Coleman, noted clinical professor of medicine, took us all on a journey that was part lecture and part quiz – with humor thrown in for good measure.” Watch the video of Dr. Coleman’s presentation! You will be uplifted to learn so much about the progress of WM treatments since the turn of the century.

The Ask the Doctor session, the traditional conclusion of an Ed Forum, is generally a spirited event when questions raised by IWFM members (either sent in advance or collected at the Forum) are selected by the moderator to put to a panel of experts comprised of doctors speaking at the Forum. As responses from the experts may not agree, often a lively discussion ensues. The role of moderator traditionally falls to Dr. Robert Kyle of the Mayo Clinic, who unfortunately was unable to attend this year. The IWFM Vice President for Research, Dr. Guy Sherwood, stepped in as substitute and received high marks for his performance.

The 2016 panel of doctors was made up of Drs. Steven Treon, Morton Coleman, Jeffrey Matous, and Jorge Castillo. With the answer to the final question of the morning, Ed Forum 2016 came to an end.

Of all the services provided by the IWFM for its members, the annual Educational Forum makes the greatest demands in terms of time and effort on the part of the volunteers who work long months in advance and never seem to sit down during the days of the Forum. Many thanks are due to all who volunteered and especially to the members of the Ed Forum Committee: Carl Harrington, Sara McKinnie, Peter De Nardis, Sue Herms, Jim Reed, Lu Kleppinger, and Lisa Wise.

And already Ed Forum 2017 is in the planning stage: Phoenix, Arizona, from May 19-21, at the Renaissance Hotel. See you there!

All PowerPoint presentation slides shown by the speakers at the Forum and select videos, along with photos taken during the weekend, are available on the IWFM website at <http://www.iwfm.com/publications/educational-forum-slides>



REPORT OF THE ADVOCACY COMMITTEE

BY JUDITH MAY, IWMF PRESIDENT EMERITA

Earlier this year the Advocacy Committee was formed by the IWMF Board of Trustees in order to establish a program that would involve the members of the IWMF in advocating for legislation of interest to patients and their families. The Advocacy Committee is led by Judith May, President Emerita of the IWMF, with the help of Bonnie Beckett and Charles Ross, Waldenstrom patients in the Washington DC area. This committee will keep a watchful eye on all pending legislation that could affect IWMF members and will send Advocacy Alerts when it is timely for you to advocate by contacting your Members of Congress.

Directions accompanying each Alert explain how to advocate by using an on-line program that is very easy to understand.

Since April of this year, five Advocacy Alerts have been sent to the IWMF membership from the IWMF office, under the signature of Carl Harrington. The Advocacy Committee has selected a number of bills in the legislature that we are now tracking. Although many of these bills have not yet been addressed in legislative committees, all are assigned to committees, and we are watching the weekly committee agendas to determine when one of our selected bills will receive attention. We then notify IWMF members of action they need to take. Your response so far has been great.

The subjects of our past Advocacy Alerts were:

- An alert on a new process to simplify contacting Members of Congress in hopes of encouraging more participation by constituents.

- An alert on possible changes in the Department of Defense budget that would reduce funding for the DOD lymphoma research program. [DOD research is separate from the National Cancer Institute research, and both programs are beneficial to WM patients]
- An alert on Oral Drug Parity.
- An alert on the Help Package.
- An alert on the Open Act.

To answer your questions as to **WHY** and **HOW** you should participate:

WHY:

To increase awareness of lymphomas on Capitol Hill.

To educate Members of Congress on the importance of lymphoma research.

To be a voice for all those patients who are not advocating.

HOW:

Write letters to your Members of Congress.

Meet with your Members of Congress if you visit Washington DC.

Call your Senators and Representatives to state your stand on an issue. Ask for their help and keep it personal.

The voice of a lymphoma patient has far greater impact than an official report. Please do your share in passing legislation to benefit WM patients.

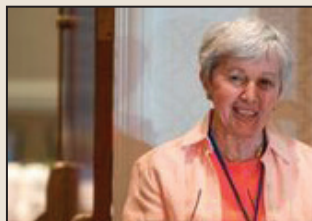
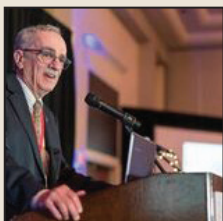
Ed Forum 2016 Additional Photos



Ali Handal



Dr. Morton Coleman



COOKS' HAPPY HOUR

BY PENNI WISNER

COLD HERB SOUPS

Until this week (late July), we have been having a Mark Twain summer (“the coldest winter I ever spent . . .”). But as you read this in September, perhaps hot weather will still be with us (This is not a political statement, just a reference to Indian summers.), and you might appreciate an opportunity to make something that requires no stove time and yet is sustaining and delicious. This is a thick soup that in smaller portions can begin a meal or act as a snack or appetizer. A larger portion could easily be all you need for lunch or supper.

Recently, I visited a friend in Sonoma County. “Do you know a cold sorrel soup recipe?” she asked. Her garden contains not one but two sorrel plants. I grew sorrel once and pulled it out since I rarely used it and was instead feeding a large community of snails.



Et voilà! The result: this smooth, pale green, thick soup is the basis as well of a versatile sauce for chicken, fish, and grilled vegetables.

What came immediately to mind was a cold soup from years ago in the *New York Times* based on orange juice, avocado, and buttermilk. (Does that sound as weird as it seems to write?) It was, however, delicious, and I thought it would be a good starting place for a sorrel version. Sorrel has a sour, tangy, lemon flavor and took a star turn in the 1970's when a French three-star chef used it to create a creamy sauce for salmon. The dairy component tames the sorrel flavor. Without sorrel, just think of this as an herb soup and use a combination of whatever fresh herbs you like. My one caveat: go easy on chives – which I normally love, but my one attempt at a chive pesto was the last.

Here we go: the basic combination includes sorrel/herbs and dairy, preferably with a tang such as yogurt, sour cream, crème fraîche, buttermilk, or labne – this last is a recent discovery. Labne (kefir cheese), to me, tastes like a cross between sour cream and cream cheese. It is made exactly as you make yogurt cheese, by draining excess liquid from kefir. You can find it in markets specializing in Middle Eastern ingredients or you can make it at home. Trader Joe's carries kefir. Line a large strainer with cheesecloth, place it over a bowl, and pour in the kefir. Tie the corners of the cloth together and hang it over a cabinet knob. Let the kefir drain a couple of hours. If you have room in the refrigerator, you can leave the kefir there overnight in the strainer, making sure the strainer does not touch the bottom of the bowl.



Ingredients for a refreshing cold sorrel and buttermilk soup with squash blossom garnish.

In addition, add seasoning (salt, of course, and cayenne – always optional but really good especially if the weather is hot), citrus (orange and lemon juice), and something for texture such as avocado, a mild tasting vegetable such as cucumber or zucchini, or both, or patty pan squash.

Squash flowers make a pretty garnish, and you could add tiny, crisp croutons. But that might involve turning on the stove, in which case, don't.

The first time I made the soup, I used twice as much orange juice (always from Valencia oranges in my world), some Meyer lemon juice (which is sweeter than regular lemons), avocado and cucumber for texture, and yogurt and sour cream for the dairy. It was quite good with a light sweet orange flavor. But the idea of adding raw squash tempted me; a second version used avocado plus cucumber and a small zucchini, less orange juice, no lemon, and buttermilk. You get the idea: herbs, vegetables, citrus, dairy. Now go play.

And use a blender for the smoothest result. Oh, one side benefit: if you add only a little dairy and just a tablespoon of lemon juice, or some lemon and orange zest, you will have a great sauce for chicken, fish, and grilled vegetables.

For those who want more specific amounts as a starting place for their own cold herb soup variation, here's what I suggest:

Strip 10 large sorrel leaves off their stems and cut the leaves into a rough chiffonade. Place them in a blender with a handful of basil leaves, one clove of garlic (peeled), a good pinch of salt and 1/4 cup buttermilk. Puree until smooth. Take a medium-sized cucumber or zucchini or patty pan squash (or combine both vegetables, using about 8 to 10 ounces of vegetable). Taste the cucumber. If the skin is tough, peel it, then cut the vegetable into chunks and add it to the blender with 1 small, ripe avocado. Puree again until smooth. Stop here if making a sauce and adjust the flavors with lemon and orange zest and juice, and salt.

To make the soup, add the juice of 1 large orange (preferably Valencia), another 1 3/4 cups buttermilk, and puree until you have a smooth, pale green, thick soup. Taste for seasoning and add salt, a pinch of cayenne, lemon, and puree again. Pour the soup into a pitcher, cover, and refrigerate until ready to serve. Taste again for seasoning and adjust as needed. The soup will keep several days, covered and refrigerated. Serves 3 to 4.

Our motto: Eat Well to Stay Well

IN THE TORCHLIGHT

ART IS MY LIFE

BY LYNN MOCARSKI MAURER



Artist Lynn Morcarski Maurer with the graphite drawing *Midlife*, one of a series featured in her one-woman show on exhibit this summer at Gallery A in Washington DC.



Lynn Morcarski Maurer, *Midlife*.

My recent art exhibit, *Passing Impressions*, at Gallery A in DuPont Circle, Washington DC, is my reconnection with nature through the metaphor of Peonies. While I cannot say my diagnosis of WM in 2007 led exactly to this stage of my art – I had a pencil in my hand at age 3 and drew many teachers' window displays by age 6 – I have learned that life is fragile and precious. This body of work is very special and likely quite subliminal.

I underwent chemotherapy in 2010 taking Arzerra (ofatumumab) rather than rituximab to which I was allergic. When I felt good, I would slide my easel over to me, versus setting-up for painting, so graphite was my medium of choice. And that was the beginning of my reconnection to the medium I have loved since I was a child and the driving force for this show.

I started with a small drawing, *First Study*, a group of peony buds, simple yet detailed like all my Trompe l'Oeil work tends to be. I love detail, shadow, and structure, and the time spent on this show took my mind off of how I was feeling physically at times, a gift for which I will be forever grateful.

First study awakened my fascination with the intrinsic nature of life, a metaphor if you will. My completed body of work has 12 pieces ranging from the smallest tiny bud

(20" x 24") to *Mid-Life*, a 42" x 42" study of a peony in full bloom. *Vulnerability* and *Differences* explore close-ups of the peonies. By observing these fragile flowers, I learned that they are driven down in moments by a hard rain only to rise again for the sun to shine on their beauty. The ground and underground began to intrigue me as well, watching miniature buds emerge each year full of freshness and vitality. At the bud stage ants love the peonies' nectar, so they debut in one of my drawings, dancing on a young bud. This drawing



Lynn Morcarski Maurer, *Vulnerability*.

In the Torchlight, cont. on page 29

caught the eye of the *Washington Post* critic Mark Jenkins:

"The defining aspect is a delicate line, as if to emulate the fragility of fresh buds and tiny creatures. The ants depicted in one drawing are not there to spoil the picnic but to represent the life force – and because a near-photographic realist such as Maurer could hardly deny that there are insects as well as flowers in the garden."

My art is my life force and will continue to be throughout my Waldenstrom's journey.

Lynn Mocariski Maurer received her BFA from the University of Nevada, Las Vegas, where she studied under the renowned Rita Deanin Abbey. She also studied *Trompe L' Oeil* with Bonnie Chumley and figure studies with So-Ho artist Jack Beal. Lynn has exhibited in numerous venues including the Corcoran Gallery of Art and Lord Fairfax Community

College. She was commissioned by the Washington National Cathedral to create the symbolic centerpieces for their nationally televised Christmas and Easter Sunday services. Lynn Maurer can be contacted at: blmaurer@comcast.net

See also:

washingtonpost.com/entertainment/museums/in-the-galleries-brentwood-arts-exchange-filled-with-flora/2016/07/15/cb2b030c-4789-11e6-90a8-fb84201e0645_story.htm

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

IWMF INFO PAKS AVAILABLE IN FIVE MORE LANGUAGES

國際華氏巨球蛋白血症基金會為病人擴充了多種語言版本的資料袋。

国际华氏巨球蛋白血症基金会为病人扩充了多种语言版本的资料袋。

IWMF élargit les langues disponibles de Paks d'Informations pour les patients

IWMF amplia disponibilità di lingue di Paks Informazioni per pazienti

IWMF amplía la disponibilidad de lenguaje de Paks de Información para pacientes

IWMF expands language availability of Info Paks for patients

The Info Pak is surely the IWMF Member Service with the longest history. It was the practice of IWMF Founder Arnie Smokler, a retired pharmacist diagnosed with Waldenstrom's macroglobulinemia, to learn as much as he could about this rare cancer and to locate other WM patients. Whenever he made contact with a new patient, Arnie would mail him or her copies of the documents about WM that he had been able to collect. These mailings, compiled and sent *gratis*, were the original Info Paks. With the formal organization of the IWMF, the practice continued of sending, at no cost, packets of helpful information in response to inquiries about WM. The abbreviated name "Info Pak" soon entered the IWMF lexicon.

Over the years, Info Paks in the English language have been sent by the thousands upon request and at no cost to the recipients. Earlier this year, the IWMF proudly announced that Info Paks in five additional languages (French, Italian, Spanish, Traditional Chinese, and Simplified Chinese) are now available for patients and caregivers. These new international Info Paks were developed with the assistance and support of the IWMF International Affiliates in France, Italy, Spain, and Taiwan.

What's in an Info Pak? Each one includes CDs with a number of our booklets, a DVD of selected presentations from the most recent IWMF Educational Forum, the most recent issue of our *Torch* newsletter, and other materials with information about Waldenstrom's macroglobulinemia and the support services and additional publications available through the IWMF for those affected by this disease.

How can you order an Info Pak in any of the 6 available languages? The easiest way is to visit iwmf.com/publications/information-packets-info-paks and select the big blue button: Order By Mail.

To order when joining the IWMF or renewing your membership, go to iwmf.com/how-you-can-help/join-iwmf/membershiprenewal-form

Orders may also be placed by telephone (941-927-4963) or by postal mail to the IWMF Office at 6144 Clark Center Ave., Sarasota, FL 34238.

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

UNITED KINGDOM

Busy times for WMUK as the deadline for the submission of evidence to our regulator, NICE, for ibrutinib in relapsed WM approached in June. This took up over one hundred hours of preparation and was supported by all the major blood charities and a signed letter from 24 of the most prominent UK WM doctors. We worked hard with Janssen to understand the challenges they face getting approval for patients.

To support the submission we carried out the largest ever UK patient questionnaire, based very loosely on a successful one for the same purpose provided by Lymphoma Canada, obtaining 280 responses in two weeks. It proved the current unmet need and the challenging nature of traditional chemo to most patients and carers. The decision meeting, which WMUK is invited to attend, is in September. We think the most likely outcome under the new system is provisional approval along with data collection over two years via the Rory Morrison WM Clinical Registry, followed by a final decision. To date already 400 patients are enrolled in the roll out of the registry.

The treatment of blood cancer drugs generally and rarer ones in particular is contentious in the UK as it lags behind many other European and North American systems, due to financial constraints rather than effectiveness. WMUK joined the Blood Cancers Alliance to try to set this straight and also supports the newly formed Blood Cancer Interest group in the UK Parliament.

Our spring meeting in the historic Assembly Rooms in Bath (see accompanying photo) was a great success with over 100 attending. Not only were the doctor presentations well received, but the patient tales of newly diagnosed, treatment on bendamustine-rituximab, the ACP196 (acalabrutinib) trial, and ibrutinib were all very moving.

On the doctor front our group has agreed to create a trials hub, led by Dr. Roger Owen, to encourage more UK trials and to get more patients on them. We are also moving towards the creation of an inclusive WM hospital list: hospitals that have enthusiasm and expertise in WM patient treatment and want to see more. We attended the International Society of Haematology meeting in Glasgow where we had a stand, and there was the first-ever WM seminar led by Drs. Shirley D'Sa and Roger Owen with over one hundred doctors and researchers attending.

The UK's unexpected Brexit decision was a blow to medicine in the UK as the European Medicines Agency, the UK



The WMUK spring meeting was held in the historic Assembly Rooms at Bath.

equivalent of the FDA which licences drugs, will move from London. The EMA has been innovative in licensing drugs for NHL and WM, and it is possible that the UK will end up both licensing and deciding reimbursement, making the pace of treatment innovation even slower.

We are looking forward to sending a healthy contingent to the 9th International Doctor-Patient Forum in Amsterdam on October 9. We have agreed to support at least one Young Investigator Award, and, if needed, give some financial help to assist junior doctors to attend the IWWM9 Workshop.

Roger Brown, WMUK, reporting from the Macmillan Cancer Centre at University College Hospital, London.



To strengthen its brand identity, WMozzies now has a new logo: a great, positive, forward-looking image, bounding ahead in knowledge, support, and advocacy for therapy.

AUSTRALIA

WMozzies has a new logo

Following the IWFM lead last year to strengthen its brand identity, WMozzies now has a new logo, a great positive forward-looking image, bounding ahead in knowledge, support, and advocacy for therapy. A competition was held to choose the new WMozzies logo. The winning design was created by the very active WMozzies member **Michael van**

International Scene, cont. on page 32

IWWM9 INTERNATIONAL DOCTOR-PATIENT FORUM

OCTOBER 9 IN AMSTERDAM

2016 IWWM9 INTERNATIONAL DOCTOR-PATIENT FORUM



October 9, 2016
Renaissance Hotel &
Conference Center
Amsterdam
The Netherlands

The IWWM9 International Doctor-Patient Forum scheduled for Sunday, October 9, in Amsterdam is jointly sponsored by the IWWMF and by Hematon, the Dutch blood cancer organization. The Forum promises a full day of presentations by outstanding international specialists and researchers in WM who have come to Amsterdam to participate in the 9th International Workshop on Waldenstrom's Macroglobulinemia (IWWM9) for physicians and researchers.

The program for the Forum is designed to address recently diagnosed WM patients as well as those who have been following their disease for longer periods of time. Both sets of patients (and their family members and caregivers) are assured of a detailed learning experience from the experts, as well as the opportunity to establish new personal contacts.

The final event of the October 9 Forum is a session of the ever-popular "Ask the Doctor" when our own Dr. Robert Kyle of the Mayo Clinic, the internationally recognized dean of WM studies, will moderate the exchange between the patients and caregivers, posing questions to the responding doctors representing Hematon and the IWWMF.

Enrollment for the IWWM9 International Doctor-Patient Forum is moving briskly as the *Torch* goes to press in late August. Those already registered are coming from the Netherlands, Belgium, France, Ireland, Switzerland, Greece, Portugal, Italy, India, Sweden, Canada, Finland, Norway, Poland, the UK, and the United States. It's time for you to make your plans, too!

Time and location: October 9, from 9:30 am to 5:00 pm in the Koepelkerk Conference Hall of the *Renaissance Hotel in Amsterdam*.

Further details: The meeting will be conducted in English and is open to all WM patients and their caregivers. Refreshments and lunch will be served, and there is **no fee** to attend the meeting.

Warning: Registration is mandatory. The Koepelkerk Conference Hall can only accommodate up to 300 people. Please register at

<http://book.pattersonkent.com/iwwm9-international-doctor-patient-forum> to ensure that a place is reserved for you. Last minute registration will also be available at the door from 8:00 am to 9:30 am pending availability.

For additional information see:

iwwmf.com/news-and-events/news/plan-attend-2016-international-doctor-patient-forum-wm



Michael van Ewijk in Ethiopia taking a bike break during his "Eyes for Africa" project.

Ewijk. Michael submitted his entry on his return from an "Eyes for Africa" project in Ethiopia. His creative work for the new logo was fitted into his busy routine as volunteer manager of the non-medical side of the charity. Michael bought a bike in Addis Ababa at the start of the project and managed to ride most days, sometimes avoiding stone-throwing boys. His rides included heading out into the Danakil Depression, the hottest and remotest part of Ethiopia, with lava lakes and salt mines. Michael, back in Australia, has now signed up for the 157 km L'Etape race, [//letapeaustralia.com/](http://letapeaustralia.com/), in the Snowy Mountains in December this year. It is being run by the organisers of the Tour de France. His team of buddies intends to ride in their own mini peloton. It will be run just like the Tour ... closed roads, transponders on bikes, and feed stations. The event has over 2,500 metres of climbing on Australia's highest mountain. It will be interesting and challenging for Michael on the demanding Col de Kosciuszko final climb. Michael is thankful that for the last two years he has been in the ibrutinib clinical trial, Australia's first WM ibrutinib clinical trial. The "trial-ist" sure is performing well!

WMozzies launch WhiMSICAL CART-WHEEL

The WMozzies WhiMSICAL CART-WHEEL research study was launched in June. This global study involves WM patients providing their clinical data to help advance current knowledge and understanding of our disease. The database has been designed to address some of the barriers facing effective research into rare cancers. It uses a privacy protected, Internet-based questionnaire. WM patients complete a questionnaire entering patient demographics, symptoms, IgM levels, full blood count information, treatments, how they were accessed, treatment side effects, as well as personal and family medical history. Information gathered will expand knowledge of the range of presentations, treatments, and toxicities experienced by patients with WM. Demonstration of any treatment



Principal Investigators of the WhiMSICAL Research study with Clinical Trial members at the Leukaemia Foundation Conference, following the session for WM Patients. Left to right: Dr. Ibrahim Tohidi-Esfahani, David Osborn (BGB-3111), Michael van Ewijk (ibrutinib), Peter Smallwood (BGB-3111), Associate Professor Judith Trotman.

disparities, coupled with information regarding treatment efficacy, may facilitate access to subsidised novel therapies. The WhiMSICAL principal investigators include Associate Professor Judith Trotman and Dr. Ibrahim Tohidi-Esfahani of Concord Repatriation General Hospital, and associate investigators Associate Professor Clare Scott, Royal Melbourne Hospital, and Associate Professor Constantine Tam of Peter MacCallum Cancer Centre. An abstract on WhiMSICAL has been submitted to the IWWM9 Workshop for WM in Amsterdam this coming October.

Andrew Warden, WMozzies, reporting.

BELGIUM

Annual symposium

Last year the board of the Flanders support group, CMP Vlaanderen, agreed to a fixed date for the annual symposium: every year on the Saturday before the Easter weekend. However, this year a number of complications developed, including keeping to the fixed date, as our small organization made plans for 2016. In July 2015 we contacted the University Hospital Brussels, Jette Campus, to host the 2016 event. During the fruitful conversation we had with Professor Schots, head of the hematology department, details were pinned down and the program was drafted broadly – topics, speakers. Then the news came that the auditoria were no longer available for the chosen date. And so it was that the symposium was held on April 16. Meanwhile, however, the board worked at half speed: several of us were sick or received treatment. But our volunteers are very persevering. The speakers were informed of the changes in good time, the topics confirmed, the printed matter rolled off the presses. Now all was ready and waiting for participants. Most registrations come in a few weeks

International Scene, cont. on page 33

before the symposium. And that was precisely the time that Brussels was anxiously avoided like the plague as a result of the regrettable events in March.

In spite of all these problems, we welcomed 161 participants: 55 patients with multiple myeloma (MM) and 19 with WM, accompanied by partners, family, friends. Also present were representatives of pharmaceutical companies and several nurses. Although we had fewer participants than in prior years, everybody was able to enjoy the instructive presentations by expert doctors.

For our WM patients, Dr. Jan Lemmens led off the morning sessions. This physician is well known not only in Antwerp, where he heads the hematological department of St. Augustinus-Wilrijk, but also by most of our fellow sufferers. They know him from previous symposia as a gifted speaker. Warm and friendly, even with a touch of humor, always responding to questions from the audience, he brought clarifying insight into the disease, diagnosis, and standard therapy of WM. Next was Dr. Fabienne Trullemans from the University Hospital Brussels, who has been a presenter at prior conferences. She is dedicated, skilled, and strongly involved with WM patients. She discussed the complications resulting from both the disease and the treatments.

After lunch Dr. Trullemans captivated the audience with a discussion of disease progression and treatment of WM patients, using examples from her daily practice. This is a topic that receives everybody's full attention.

The last subject of this fine day brought the MM and WM patients together. Professor Schots and Dr. Fostier, both of the Myeloma Clinic of UZ Brussels, concluded with a presentation on clinical trials. What are clinical trials? How and where can you participate? What are the benefits they offer to the participants?

Those present went home with a reassured feeling and with the hope of an early reunion with their fellow sufferers.

Health policy and WM

As CMP is an association which deals with two disorders, multiple myeloma and WM, one sees very well a distinction between the two regarding awareness and access to new therapies. Little or no clinical studies take place for WM patients. There is slow access to new treatments which have mostly been approved for other similar diseases. The cost-benefit balance is quickly made for us at a time when economizing stands high at the top.

And this is why our CMP tries to improve the quality of life of its members by supporting them, by organizing symposia where they can get medical information, and by the regional meetings where exchange of experiences and friendship is so important.

Joanna Van Reyn, CMP Vlaanderen, reporting.

CANADA

The WM Foundation of Canada wishes to thank **Bert Visheau** for his 16 years of dedication and contributions to the WM Board of Directors. As one of the first directors elected to the Board, he has been an incredible asset in sharing with us the latest abstracts on new research for WM. Bert has stepped down to focus on family but will continue to join our support group meetings. We all extend our gratitude and wish him and his family all the best.

We are very excited to welcome two new members to our Board, **Raffaella Mercurio** and **Ian Roberts**. We thank them very much for volunteering to ensure we continue to have a strong and active Foundation representing all Canadians living with Waldenstrom's macroglobulinemia.

Pay it forward: Volunteer now!

We continue to look for people across Canada who can offer any time or expertise on special events, medical research, Facebook monitor, or assist in fundraising. If anyone is interested in becoming a part of our team and helping to make a difference, please contact Arlene Hinchcliffe at ahinchcliffe@wmfc.ca or 905-337-2450.

The WMFC would like to express our gratitude to all Canadians who have generously donated to our Research Fund over the years. We have to date sponsored over \$600,000 in research, primarily in Canada, and are proud of our commitment in helping the greater WM community find the cause, new treatments, and ultimately a cure for this rare cancer. To continue to do so we need your help today. We only reach out to our WM members, their families, and friends for support. The Toronto chapter of the WMFC has held a fundraiser in their community every other year since 2008 and has raised in excess of \$100,000 to date for research. It can be done.

You are the one living with WM and only you can help make a difference in how you live your life. Reach out to your family, friends, and community to give us the opportunity to fight Waldenstrom's macroglobulinemia now.

Arlene Hinchcliffe, WM Foundation Canada, reporting.

ITALY

Milan meeting with patients and physicians

Almost one year after our meeting with Dr. Steven Treon, Director of the Bing Center for WM at the Dana-Farber Cancer Institute in Boston, a major new initiative was organized by the Blood Diseases NPO - WM-IT Support Group. The opening event was the Patient and Doctor Meeting on Macroglobulinemia Waldenström held on Saturday May 28 at the Conference Hall of the Milan Niguarda Hospital. The meeting addressed patients, relatives, and caregivers interested in hearing from doctors and researchers about the latest developments in WM research news and the therapeutic

possibilities for this rare pathology. On this occasion the five booklets of the IWmf translated into Italian were introduced. The booklets are customized, printed, and made available at no cost, both in print and online, at:

iwmf.com/publications/download-IWmf-publications

A warm and welcoming greeting by Dr. Enrica Morra opened this program designed to explain and explore basic immunology, clinical tests, blood tests, review of possible treatments – and to provide time for questions and answers. The following doctors and experts participated:

Dr. Maddalena Mazzucchelli of Niguarda Hematology Day Hospital summarized the IWmf publication program and explained the content of each booklet in non-technical terms, underscoring as well the general characteristics, possible causes, and the clinical manifestations of the disease.

Dr. Alessandra Tedeschi of Niguarda Hematology detailed the treatments currently used for WM depending on different types of patients. Her presentation analyzed the characteristics, the effects, and the responses to different treatments and focused mainly on the latest advances in biological and therapeutic research.

The topic of the latest treatments was then expanded by

Dr. Aldo Roccaro, a researcher who is currently working

within the Lombardy hematological network in Brescia after some years at the Dana-Farber Cancer Institute in Boston. Dr. Roccaro explored the theme of translational research, which refers to making pre-clinical studies the basis of future therapeutic perspectives. He also gave examples of new studies current in the United States.

For every single presentation attendees had an opportunity to pose questions to the speakers, in line with the purpose of the Meeting: to create an opportunity for an open dialogue with physicians (often not feasible during outpatient visits) and for focusing on the concerns of the patient, the details of therapies, and practical tips for a healthy lifestyle and the patients' well-being.

Upcoming activities

The Patient and Doctor Meeting was followed by a working meeting of the WM-IT Group to review projects carried out by the Group during the past year and to plan future activities. The group's unanimous decision was to be represented by our professional members at the 9th International Workshop on Waldenstrom's Macroglobulinemia (IWWM9) and by patients and caregivers at the IWWM9 International Doctor-Patient Forum. Both events will be held during October in Amsterdam. (See page 31 for more information)

Ermanno Chiavaroli, WM Italy reporting.

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

PLEASE NOTE!

Contact information for all support groups is found on iwmf.com under GET SUPPORT.

Details of support group meetings and other upcoming events are posted on iwmf.com under EVENTS. Please check there to confirm details of future events.

CALIFORNIA

Sacramento and Bay Area

A big crowd met in February at Stanford to hear Dr. Michaela Liedtke give an "Introduction to the Principles of Clinical Trials." After her presentation Dr. Liedtke answered many general questions about WM. Stanford is conducting trials of ibrutinib, and several people from the group are in the trials. One fact that particularly impressed the members was the cost of drug trials. Running a trial is so expensive that it usually requires financial support from a drug company. The group was well represented with 15 members at the June IWmf Educational Forum in Providence, RI. The group's September 18 meeting at the Kaiser Vallejo will provide the opportunity for members to reflect on and share their lasting impressions from the Forum. The group will meet from 1:30-



The Sacramento and Bay Area Support Group was well represented at the June IWmf Ed Forum in Providence, RI, with fifteen attendees. Many of them met for this group picture.

Front row: Dick Jordan, Cindy Jordan, Alyce Rossow, Debi White, Sally Simpson, and Kristine Satterwhite.

Back row: Chuck Simpson, Terry Rossow, Beverly Bloss, Wally Conroe, and Tom White. Others attending the Forum but not present for photo: Jennifer Hoegerman, Michael Luttrell, Susan May, and Tina Ann.

Support Group News, cont. on page 35

3:30 in Conference Room 9 on the second floor of the Kaiser Hospital Tower.

Southern California

The Southern California Support Group had its biannual meeting in May at the Brentwood Public Library. About 40 WMers and caregivers were in attendance to hear speaker Dr. James Berenson address the group about the various treatments for WM. Dr. Berenson's presentation was followed by a lively Q&A and then a tasty lunch. Dr. Berenson works in private practice at the Institute for Myeloma and Bone Cancer Research in West Hollywood and specializes in the treatment of MM, MGUS, amyloidosis, and WM. Debra Berenson, Dr. Berenson's wife, authored the book *I have WHAT? Multiple Myeloma? Waldenstrom's Macroglobulinemia? Amyloidosis? MGUS?* The book is a collection of candid stories told by patients about these diseases. Watch the EVENTS calendar on iwmf.com for an announcement of the next SoCal Support Group meeting, scheduled for October or November.

COLORADO & WYOMING

Elsa Bradley is joining Cindy Furst and Bill Bass as a new co-leader. Here is her self-introduction: "After teaching for 36 years, in Florida and Colorado, my husband Gary and I sold our house and bought an RV, beginning an adventure as full time RVers in 2005. We worked summers near National Parks. In 2007, while working in Maine, I experienced severe anemia, requiring a blood transfusion. After the usual tests, I was diagnosed with 'a kind of NHL.' We returned to Colorado Springs so I could be treated for WM.



Elsa and Gary Bradley. Elsa is a new Support Group Leader for Colorado.

I was then good to go for over five years, and we continued our travels, finally settling in Denver in October 2012 and selling our RV. I am doing well now on Imbruvica. I enjoy working out, walking, singing in my church choir, wildlife photography, volunteering with Project Cure. I look forward to working with Cindy and Bill!"

CONNECTICUT

Eleven patients plus spouses and caregivers gathered at the Westport Public Library in early May. The bulk of the meeting time was devoted to discussing individual WM stories and treatments. The remaining 45 minutes were devoted to the DVD of Dr. Castillo's recent IWMF Ed Forum presentation. It contained a wealth of important information. This format is typical of our twice-yearly meetings. Afterwards, a group

went out to lunch. The next meeting is planned for October 22 in Cromwell, CT.

ILLINOIS

Chicago Area and SE Wisconsin

The group held their annual spring meeting on April 30. Fifty-eight attendees enjoyed the talk by a favorite speaker, Dr. Shou Ma, who now has spoken twice to the group. Dr.



Dr. Shou Ma with Don Brown, Support Group Leader of the Chicago area group.

Ma is a hematologist-oncologist at Northwestern Memorial Hospital and an assistant professor in the Department of Medicine. Interestingly, Dr. Sherine Elswa, a WM researcher from Northern Illinois University, attended the session as well. She has been very engaged with our group for several years and has been doing WM research supported by a grant from the IWMF

(see the Research page on the IWMF website for details). Dr. Ma made a wonderful presentation and then led a very interactive and informative Q&A period. Following Dr. Ma's formal presentation, it was nice to see both doctors meet and communicate for the first time. Our summer picnic took place in August (details in the next *Torch*!). And watch the EVENTS calendar on iwmf.com for the announcement of the fall meeting.

INDIANA

The Indiana IWMF Support Group met in June at the Leukemia & Lymphoma Society office in Indianapolis. There were 12 people attending to hear a report from group members who were in Rhode Island at the IWMF Educational Forum. Six from Indiana attended this year. There was much discussion and many questions after an interesting report on the Forum. Our usual format includes breakfast snacks, coffee, water, and a time for sharing. Two new members joined the group, and the sharing was rich with stories and catching up since the last gathering. The Indiana Support Group meets three to four times a year. There are plans for a September meeting with a pharmacist as speaker. Check EVENTS calendar on the IWMF website for the date. Waldenfriends (a term introduced officially by President Carl Harrington) are all invited. Our new name embraces WM patients, friends, and family from Indiana or nearby, or anyone visiting the area.

NEW YORK

Eastern NY and Western New England

April 2 was the date of the annual restaurant "Pig Out Luncheon." This year the group voted to go to the Capital

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The large audience gathered in Philadelphia to hear Dr. Castillo.

Buffet in the town of Colonie, NY. While the Capital Buffet features Chinese food, there are several varieties of sushi, Hong Kong noodles, and ample types of “American” dishes (including shrimp, salmon, and pizza). About 20 members gathered to enjoy all of the food plus lots of conversation (even some group “business”). A decision was made to show an IWMF Ed Forum DVD at the next meeting. Accordingly, at the June meeting at the ACS Hope Club in Latham, NY, we showed Dr. Morie Gertz’s “Garden Talk” from the 2015 Dallas Ed Forum. Everyone enjoyed this DVD, even those who had seen his presentation previously. Dr. Gertz’s message was especially of interest to the new support group members. After the DVD, attendees “adjourned” for lunch. There is always food!

Rochester, Western and Central NY

This small group has planned an outing at a restaurant for September. Members try to get together twice a year, but many are getting older, and for some other health issues have surfaced which prevent getting out as much as they used to.

**EASTERN OHIO, WESTERN PENNSYLVANIA
& WEST VIRGINIA**

In early April, group members gathered in Pittsburgh at the home of **Marcia** and **Glenn Klepac** to reconnect after our winter break and to de-stress through mindful meditation practice. Following appetizers and casual conversation, Deanna Burkett, MA, MS, RYT, skillfully led the group through short exercises as an introduction to mindful practice. Following each meditation, members processed the experience by

sharing personal reactions and thoughts about the usefulness of the meditation. The tranquility created through the meditation carried through to the delightful potluck dishes that highlighted salads and desserts and through informal group sharing. Individuals discussed their latest WM updates and adventures for feedback and support. A very relaxing afternoon! The following month, members ventured to a new location in Canfield, OH. The small, but mighty, group of 8 warmly welcomed a new member and caregiver at the beautiful new Canfield Library. For three hours, until closing time, veteran WMers reflected back to their individual experiences and resources to help address the burning issues of the new member related to symptoms, treatment, remission, and healthcare options. The personal rewards of this meaningful get-together were clearly felt by veteran WMers and the new member and caregiver. All left with a deep sense of connection and gratitude for the opportunity.

PENNSYLVANIA

Philadelphia

In March the Philadelphia group was delighted and honored to host Dr. Jorge Castillo of the Dana-Farber Cancer Institute at their March meeting. What an incredible event! Dr. Castillo’s presentation on “Genomic-based Advances in WM” was extremely well received and chock full of helpful information. He presented at a very high level, and the group was completely engaged. Members peppered Dr. Castillo with thoughtful questions throughout his PowerPoint

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Dr. Jorge Castillo of the DFCI with IWMF President Carl Harrington and Philadelphia Support Group Leader Lisa Wise.

talk. It felt very interactive and inclusive with both newly diagnosed members and “old veterans” benefiting from the material being shared. Many folks expressed the feeling that Dr. Castillo’s presentation offered them an invaluable and enlightening overview of their disease, and they deeply appreciated his fresh perspective and tireless, dedicated efforts toward finding new treatments. A huge thank-you to Carl Harrington for securing a grant to have Dr. Castillo’s entire presentation filmed! Dr. Castillo’s trip to Philadelphia and the taping of his presentation were made possible by an unrestricted educational grant from Idera Pharmaceuticals, Inc. All are grateful to Idera for their generous support. Thanks to Carl’s invaluable efforts, WMers worldwide can view Dr. Castillo’s presentation on the IWMF website at iwmf.com/news-and-events/news/watch-dr-castillo-discuss-genomic-based-advances-wm Fifty folks turned out for Dr. Castillo, many traveling long distances from all parts of Pennsylvania, New Jersey, Delaware, and Virginia! Most people arrived early and many stayed late so there was lots of informal chatting and catching up and welcoming of newly diagnosed members. Fresh bagels, muffins, fruit, and coffee and pre-printed nametags created a warm and welcoming atmosphere that enabled easy camaraderie. All in all, a complete success; the group feels very privileged and grateful that Dr. Castillo would make the special trip to Philadelphia and that we were able to film the meeting so others can benefit from his incredible presentation. Next step: make yourself a cup of tea, sit back in your favorite chair, and enjoy this most informative video.

SOUTH CAROLINA

The South Carolina Support Group will have its fall meeting on 24 September at 2:00 pm in Greenwood. The meeting will be held in the Cancer Center of Self Regional Hospital, 1325 Spring Street, and **Roger Robinette** will share information gathered at the Ed Forum in Providence. Roger recalls his involvement with WM support groups since 1997 after locating Arnie Smokler via the Internet and subsequently attending his first Ed Forum. Roger and **Barbara Robinette**, along with **Paula Austin**, serve as group co-leaders. They hope to have a good turnout and to create the opportunity for group members and newcomers to share stories and progress made. Greenwood has several nice hotels, golf courses, and many good restaurants for those traveling from a distance.

WASHINGTON

This spring, the Washington State group met with Margaret Metzger, oncology social worker with the Pacific Medical Center, who discussed in detail so many aspects of the WM cancer journey, from stress to financial considerations, to insurance. The group also hosted Dr. Ed Libby from Seattle Cancer Care Alliance. The entire time was spent asking questions about WM and related matters. There is great excitement for the November 5 meeting featuring the appearance of Dr. Jorge Castillo from the Dana-Farber Cancer Institute in Boston.

NORTHERN VIRGINIA, WASHINGTON DC & WESTERN MARYLAND

In April the Northern Virginia IWMF Support Group cosponsored a program in cooperation with the National Capital Chapter of the Leukemia & Lymphoma Society (LLS). Tracy Orwig, the LLS local representative who attended the 2015 Ed Forum in Dallas, TX, made this joint program possible. Dr. Kenneth David Miller, MD, hematologist-oncologist with the Alvin and Lois Lapidus Cancer Center at Sinai Hospital in Baltimore, gave a talk entitled “Seasons of Survivorship.” Dr. Miller, who is widely acclaimed as an expert in all aspects of cancer survivorship, was joined by his wife, Joan Miller, herself a cancer survivor. Ms. Miller, who holds a Master’s Degree in Counseling and Consulting Psychology, wrote a book about their experiences with the title *Healing Grief: A Story of Survivorship*. The Millers suggested that every cancer patient should create a survivorship plan that addresses the medical, emotional, spiritual, and financial aspects of living with cancer. A question and answer period followed this presentation, allowing time for members’ specific concerns and stories.

THE IWMF LIFELINE

BY WANDA HUSKINS, RN, IWMF TRUSTEE

The diagnosis of a rare cancer sounds unusual, frightening, and alienating. From the moment we hear that we have been diagnosed with the rare cancer Waldenstrom's macroglobulinemia, we face challenging questions, worries, and fears. There is no shortage of anxiety arising from a life with WM. Where, we ask, do we turn when our lives are turned upside down?

For me, as for many, the IWMF offered the necessary refuge to cope with and adjust to the implications of living with WM. Anguish was ultimately replaced with real hope. Through its services for the education of patients, the research it funds, and its unshakable sense of community, the IWMF affords the golden opportunity not to just live with WM but to live well in spite of it.

Our diagnosis becomes a lesson in acceptance, adaptability, and reassessment as time moves on. Seeking or maintaining a balance may seem unobtainable at times. But you are not alone. Peer support has been a cornerstone of the IWMF since its inception. As a recently elected Board Member of the IWMF, I was honored, and am enthusiastic, to be appointed Chair of our IWMF LIFELINE Committee, a member service of "one on one" peer support.

The IWMF LIFELINE offers those with a specific concern the opportunity to reach a "Waldenfriend" volunteer who has faced a similar issue and can offer peer support and guidance on an individual basis by phone and email. LIFELINE volunteers are committed to helping other Wallies "get through" issues they themselves have faced. We currently have 25 different volunteers available for 23 types of treatments and 28 more volunteers handling 15 significant issues pertaining to WM. New topics that have been added include Bing-Neel Syndrome, Eye Issues, Familial WM, and Lymphadenopathy/Bulky Disease. We also provide an International LIFELINE section.

The goal for the LIFELINE is to offer quality help to all in need. My responsibility is to monitor the LIFELINE List and to locate new volunteers, particularly when new treatment agents are added. Volunteers are encouraged to reach me in situations that require further assistance. I will be in contact with volunteers periodically to seek advice on how to improve this service.

Psychologist Dr. Naomi Schechter, a WM patient and IWMF volunteer, and I are planning to offer our LIFELINE volunteers a primer on listening skills for even more effective communication with those who contact them. Naomi is certified in EMDR, an effective trauma treatment, and experienced in hypnosis and other stress management methods.

Our LIFELINE volunteers are not medical experts; however, their assisted support has been shown to give many in our community the "one on one" guidance needed to understand a situation. In addition, the IWMF has a strict privacy policy posted on our website: iwmf.com/privacy-policy

The IWMF LIFELINE can be easily found on our website, where it is updated regularly, displayed in alternating bands of orange and white: iwmf.com/sites/default/files/docs/documents/IWMF_LIFELINE.pdf

A printed copy of the LIFELINE is also available in the Info Paks from IWMF headquarters and appears twice a year in the *Torch* (see this issue, pages 39-40).

Please take a moment to look through the List and to take note of the wonderful volunteers who have offered their service to our cause.

And, should you not find a topic that you feel should be on the LIFELINE List, don't hesitate to contact me. In addition, I'm looking for LIFELINE volunteers for many of the newer agents.

Wanda Huskins, LIFELINE Committee, lymphomation@yahoo.com (845) 664-3077

IWMF LIFELINE Treatment

Treatment	Contact	E-mail	Telephone
2-CDA (Cladribine with Rituxan)	Bernard Swichkow	bswichkow@braae.com	305-670-1984
Bendamustine	Leslie Neustadt	lesbn96317@aol.com	518-374-8607
Bendamustine & Rituxan	Vicki Marino	Vlm4588@yahoo.com	330-393-4588
Bortezomib, Dexamethasone, & Rituxan (BDR)	Ron Linford	Rongl@aol.com	865-657-9895
CaRD (Carfilzomib, Rituxan, & Dexamethasone)	Mindy Caplan	mindycap@yahoo.com	504-309-2247
Chlorambucil	Jack Cadigan	ceco@alaskan.com	907-321-3466
Oral Cytosan	Lou Birenbaum	lbirenbaum@aol.com	314-961-5591
DRC (Dexamethasone, Rituxan, & Cytosan)	Julie Tracy	jatracc1@pacbell.net	559-627-5471
Everolimus (RAD001)	Larry Adam	admiralsiker@hotmail.com	608-774-3949 608-872-2263 608-754-3949
Fludarabine & Rituxan	Jerry Block	jblock35@comcast.net	301-460-9799
Ibrutinib (Imbruvica)	Mitch Orfuss Leslie Slate	morfuss@aol.com lsusanslate@aol.com	646-352-4476 310-717-0129
IMO-8400	William Block	wblock@msn.com	206-399-3033
Ofatumumab	Rob Clark		518-298-2611
R-CVP	Allen Weinert	anweinert@gmail.com	760-704-1344
Lenalidomide	Chris Patterson	Christopher_patterson@dfci.harvard.edu	617-632-6285
Rituxan	Allen Weinert Mel Horowitz	anweinert@gmail.com wmcure@yahoo.com	760-704-1344 518-449-8817
Rituxan Maintenance	Sue Herms	suenchas@bellsouth.net	843-801-0989
Thalidomide	Mel Horowitz	wmcure@yahoo.com	518-449-8817
Velcade subcutaneous	Allen Weinert	anweinert@gmail.com	760-704-1344
Allogenic stem cell transplant	Eileen Sullivan Melissa Sawyer	Ebsullivan27@gmail.com sawyerirish@aol.com	617-625-6957 303-979-1765
Autologous stem cell transplant	Scott Blazek	mandsblazek@aol.com	651-730-0061
IVIg	Ron Linford Peter DeNardis	rongl@aol.com pdenardis@comcast.net	865-657-9895 724-462-9458 412-624-1092
Plasmapheresis	Fred Bickle Fay Langer	Ffb134@msn.com Fhlander@gmail.com	805-492-4927 904-625-3135

Other WM Issues

Issue	Contact	E-mail	Telephone
Amyloidosis	Leslie Neustadt	lesbn96317@aol.com	518-374-8607
Bing-Neel	Julie Davidson	jefdavidson@icloud.com	615-614-3440 615-429-2017
Caregiving	Dudley Killam Susan Stoel Jeff Prupis Megan Davey Lynn Bickle	DKillam@aol.com carlstoe@hotmail.com jeffprupis@yahoo.com megandavey30@yahoo.com Ffb134@msn.com	818-952-1812 734-254-0509 845-664-3078 901-212-8240 805-492-4927
Fatigue due to WM	Marcia Klepac	marciaklep@hotmail.com	724-433-5687
Cryoglobulinemia	Fay Langer	fhlanger@gmail.com	904-625-3135
Emotional aspects of dealing with WM	Wanda Huskins Naomi Schechter	wmmnml@gmail.com schechtern@earthlink.net	845-664-3077 212-666-7136

Eye Issues in WM	Maureen Hanley	mmhanley@hotmail.com	617-733-9043
Familial WM	Marcia Klepac Wanda Huskins	marciaklep@hotmail.com wmnmzl@gmail.com	742-433-5687 805-664-3077
DLBCL transformation	Penny Hayes	pennyphayes@gmail.com	806-215-6231
Lymphadenopathy/Bulky Disease	Wanda Huskins	wmnmzl@gmail.com	845-664-3077
MGUS	Mary Beth Nivens	mbnev@sbcglobal.net	203-375-7748
Newly diagnosed	Wanda Huskins Joel Rosenbilit	wmnmzl@gmail.com rosenblitj@gmail.com	845-664-3077 503-365-7074
Peripheral neuropathy	Gayle Backmeyer Tom Hoffman	divagayle@comcast.net thh97@msn.com	765-962-3746 501-868-8305
Watch & wait	Mel Horowitz Renee Paley-Bain Joel Rosenblit	wmcure@yahoo.com paleybain@aol.com rosenblitj@gmail.com	518-449-8817 203-744-7851 503-365-7074
Young WM	Ryan Scofield Bob Bailey Laura Bailey Scott Blazek	ryanscofield@gmail.com Bbailey@rune2e.com Laurabailey64@gmail.com mandsblazek@aol.com	312-576-9429 770-633-3536 770-361-4859 651-730-0061

US LIFELINE Specialty Topics

Topic	Contact	E-mail	Telephone
Affordable Care Act	Leukemia & Lymphoma Society		800-955-4572
Clinical Trials	Tom Hoffman	thh97@msn.com	501-868-8305
Hearing impaired TTY Facility	Betty McPhee	bjmcphoe@hotmail.com	647-348-7440
Military Veterans	Daniel Costigan Glenn Ross	dancostigan@hotmail.com GSR060647@aol.com	952-841-0174 305-808-4170 214-317-9494
Social Security Disability	Howard Prestwich	prestwichh@gmail.com	815-233-0915

International LIFELINE

Country	Contact	E-mail	Telephone
Arabic speaker	Sherine Elsawa	selsawa@niu.edu	815-753-7839
Australia	Peter Carr Andrew Warden	petercarr@iprimus.com.au andrew.warden@bigpond.com	+61 7 5529 0518 +61 2 9974 2277
Belgian speaker	Joanna Van Reyn	Joanna.vanreyn@comp-vlaanderen.be	+32 93 354660
Canada LIFELINE	http://wmfc.ca/local-support/canadian-lifeline-contacts/		
Dutch speaker	Paul Theuns	pjtheuns@planet.nl	
Finnish speaker	Veikko Hoikkala	veikko.hoikkala@dnainternet.net	+35 85 500484864
French speaker	Patrice Ostermann	Pat.ostermann@orange.fr	+33 6 22 34 74 26 +33 5 61 71 25 25
Japanese speaker	Tony Undo Otani (U.S.)	adyna@msn.com	562-924-0150
Spanish speakers (all in U.S.)	Peter Mitro Betty Beazley Leon Maya Brad Smith	stonehill@earthlink.net betsybeazley@gmail.com leonmaya55@gmail.com becandbrad@gmail.com	216-591-1004 561-495-4299 865-694-9581 808-594-8914
Sweden/Norway	Anne Odmark	Ag.odmark@gmail.com	+46 18 140513
UK LIFELINE	http://www.wmuk.org.uk/about-wm/links		

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