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DOCTOR ON CALL: STEPHEN M. ANSELL, MD, PhD



Dr. Stephen Ansell during a break at the IWMF Educational Forum. Breaks in the formal program provide attendees at an Ed Forum the opportunity to speak with and address their questions to the speakers.

IMMUNOTHERAPY FOR WALDENSTROM MACROGLOBULINEMIA

Stephen M. Ansell, MD, PhD, is a Consultant in the Division of Hematology, Mayo Clinic, as well as Professor of Medicine in the Mayo Clinic College of Medicine. Dr. Ansell is also Chairman of the Scientific Advisory Committee of the International Waldenstrom's Macroglobulinemia Foundation.

Waldenstrom macroglobulinemia (WM) is a cancer of lymphocytes and plasma cells. These cells are part of the body's immune system,

and when lymphocytes and plasma cells have become malignant, the immune system is still able to partially regulate their growth. Immune cells and cancer cells interact, and this interaction plays a role in controlling the progression of WM. It is usual that B-cells, plasma cells, and immune cells, such as T-cells and macrophages, interact in the bone marrow, lymph nodes, and spleen. Immunotherapy is a way to utilize this interaction and enable the immune system to more actively target cancer cells.

There are three major ways through which immunotherapy attempts to achieve this: first, by helping the immune system target the cancer cells; second, by reactivating immune cells that are suppressed; or third, by bypassing the barriers that suppress the immune system.

STRATEGY 1 – TARGETING CANCER CELLS

A common way to allow the immune system to more effectively visualize and target the cancer cells is to activate the immune system by the presence of a monoclonal antibody bound to the outside of the malignant cell.

Treatments such as rituximab (Rituxan) target CD20, a protein on the outside of B-cells, including malignant B-cells. When rituximab attaches to CD20 on a WM cell, immune cells are activated and kill the antibody-coated WM cell. The immune cells that participate in this process include macrophages and monocytes, as well as natural killer (NK) cells and T-cells that kill cells with antibodies on their surface. This process is called *antibody-dependent cytotoxicity*, meaning that antibody stuck to the cell targets the cell for destruction by the immune system.

Rituximab is now part of standard therapy for WM and is used either alone or in combination with chemotherapy. Rituximab is also commonly used as maintenance treatment after initial chemotherapy. This strategy of targeting cancer cells by using antibodies is being improved by the development of new antibodies that target CD20 or that target other proteins on the

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surface of cancer cells. New anti-CD20 antibodies in use in B-cell malignancies include ofatumumab (Arzerra) and obinutuzumab (Gazyva).

STRATEGY 2 – REJUVENATING A SUPPRESSED IMMUNE SYSTEM

The immune system in WM is not normal. Cancer cells make many immunologically active proteins (cytokines are an example) that suppress the function of immune cells. Also, immune cells can become worn out and eventually exhausted by continually responding to cancer cells. Suppressed or exhausted immune cells are unable to effectively kill cancer cells.

This second immunotherapy strategy involves treatment approaches to reinvigorate immune cells that have become suppressed or exhausted. This type of treatment is typically called *immune checkpoint blockade (or immune checkpoint inhibitor)* and uses antibodies to block the signals that switch the immune system off.

Immune checkpoint blockade is now widely used in the management of cancer patients. The exhausted and suppressed immune cells often have receptors on their surface, among them a receptor called PD-1. Signals through PD-1 cause the cell to become suppressed. PD-1 normally is important in maintaining self-tolerance, preventing autoimmunity, and protecting tissues from immune collateral damage. Unfortunately, PD-1 can be “hijacked” by cancer cells, in effect “hiding” them from the immune system cells. An antibody that blocks signaling through PD-1 allows the immune cells to “wake up” and “see” the cancer cells, thereby more effectively targeting them.

Treatments that block PD-1 include antibodies such as nivolumab (Opdivo) and pembrolizumab (Keytruda). Nivolumab and pembrolizumab have shown promising efficacy in other lymphomas and are just now being introduced into treatments for WM. Results with these PD-1 inhibitors in WM are eagerly awaited.

STRATEGY 3 – OVERCOMING IMMUNOLOGICAL BARRIERS WITH CAR T-CELLS

The immune system often struggles to directly attack cancer cells. This is because the cancer cells are somewhat “invisible” to the immune system since they lack proteins on their surface that identify them as “foreign.” Also, as mentioned above, proteins produced by cancer cells often significantly suppress the immune system. A third strategy to overcome the immune suppression and to target the malignant cell more effectively

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is to put an artificial “docking site” into the patient’s T-cells.

This “docking site” allows immune cells to directly bind to cancer cells even when they lack proteins that label them as “foreign,” and therefore enables immune cells to kill the cancer cells more efficiently. A CAR (chimeric antigen receptor) T-cell is a T-cell that has had an artificial receptor (or artificial “docking site”) introduced into it. This receptor includes an automatic activating protein as well so that the T-cell becomes activated when the receptor binds.

These CAR T-cells typically target CD19 (a protein on B-cells) and will bind directly to any cell that has CD19 on the cell surface. The T-cells are automatically activated when they attach to cancer cells, and these activated T-cells kill the malignant B-cells. This treatment involves taking a patient’s T-cells from his or her peripheral blood, growing them in the lab to increase their numbers, and introducing the chimeric receptor into the T-cells. The CAR T-cells are then reinfused into the patient, where they recognize and attack the cancer cells.

So far, CAR T-cell treatment has proved very promising in B-cell malignancies, but it has only been tested in a few patients with WM. This treatment also has significant risks. A cytokine release syndrome (fevers, chills, low blood pressure, possible heart and breathing issues), as well as neurological toxicity (confusion, speaking problems, unresponsiveness), sometimes results but resolves with appropriate support. Interestingly, these toxicities are often seen in patients who have the best clinical results. Because of these potential side

effects, CAR T-cell therapy needs to be given in centers with significant expertise in this area.

LOOKING TO THE FUTURE

All told, the future for immunotherapy is very promising, and these novel treatment strategies are currently being tested in clinical trials. At this point, multiple approaches to reactivate and target the immune system are being explored, and we will need to wait and see which will be most successful. In the near future, we anticipate that these treatments will be useful either alone or in combination with other treatment approaches for patients with WM. We anticipate that activating the immune system to directly target B-cells and plasma cells will result in improved treatments for WM patients.

TERMS TO KNOW

Immunotherapy – treatments that use the immune system to fight cancer.

Antibody – an immune molecule that attaches to cells, bacteria, or viruses that the body sees as foreign (man-made versions include rituximab).

Immune checkpoint inhibitors – antibodies that block signaling by molecules (such as PD-1) that suppress immune cells (examples are nivolumab and pembrolizumab).

Receptor – a protein on the cell surface that receives messages from outside the cell (e.g. CD19, CD20, and PD-1).

Chimeric antigen receptor (CAR) – artificial receptor put into T-cells to cause them to interact with cancer cells.

PRESIDENT’S CORNER



Reason #1 for the success of the IWMF: We pay it forward. You know the concept – the beneficiary of a good deed, rather than reciprocating to the benefactor, performs a good deed for someone else.

Dr. Eva Hoff Wanderaas from Norway just paid it forward. She wrote: “In 2008, I discovered IWMF-Talk on the Web. That was in a period when I realized

that I had to learn more about my disease myself and take part in the decisions of the treatment. I translated the IWMF Fact Sheets into Norwegian as a ‘thank you’ for all the information I’ve gotten from the IWMF and for all IWMF does in granting money for research work.” Now other Norwegians with WM will have easy access to valuable information.

Let’s connect that example of paying it forward to the 2017 IWMF Educational Forum in Phoenix. As I listened to the enthralling presentations, I couldn’t help thinking about how much progress we have made and how that had everything to do with the willingness of WMers to pay it forward to help other WMers. The knowledge we have gained about our disease, the support systems we have expanded, the better treatments with more tolerable side effects we have available now, and the growing number of doctors who are committed to searching for a cure – all are testament to an unselfish willingness to help others with this disease.

So, what can you do yourself to continue this tradition of paying it forward?

Participate

- Come to your Support Group meetings.
- Participate in IWMF Connect and share your experience and knowledge (see page 11).

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- Join a clinical trial if you need treatment.
- Join the WHIMSICAL patient database (see page 28).

Volunteer

- At your Support Group. Help your Support Group Leader. Bring refreshments, help with AV or whatever is needed.
- Fundraising. Help the Fundraising Committee raise the money we need or make thank you calls to donors. Contact Michael Sesnowitz at mlsecon@gmail.com
- The *Torch*: Have writing or proofreading skills? Please let *Torch* editor Alice Riginos know at ariginos@me.com
- Have other skills to offer? Contact Jennifer Silva, the IWMF Operations Manager, at jsilva@iwmf.com

Donate

- Give as generously as you can to reinforce the IWMF vision: Support everyone affected by Waldenstrom's macroglobulinemia while advancing the search for a cure.
- Ask your friends and family to support the IWMF. I just asked my friends and family to support the Walk for Waldenstrom's 5K at the Phoenix Ed Forum, and they helped me raise nearly \$5,000.
- Join the Ben Rude Heritage Society with a legacy gift. Go to iwmf.com/how-you-can-help/ben-rude-heritage-society
- Best of all, make your donation a multi-year pledge!

It takes our whole family of WMers working together to pay it forward to cure our disease!

Getting back to the 2017 IWMF Educational Forum, it was a huge success – our biggest ever with 313 attendees. And attendees gave it an overall 4.85 rating out of 5.0. You really can't do better than that!

Read more about the Ed Forum on pages 14-19. And visit the IWMF website at iwmf.com to see PowerPoint slides of all the presentations and selected videos.

Even if you just attended the Phoenix Educational Form or have attended previous Ed Forums, think about coming to the 2018 IWMF Educational Forum at the Westin O'Hare in Rosemont, IL, right by the Chicago O'Hare International Airport. Ed Forum 2018 will be held May 18-20. We have a great hotel rate of \$125 a night and a daily parking fee of only \$5.00 for anyone who drives. And the hotel will honor our rate for 3 days before and 3 days after for a limited number of rooms in case you want to extend your trip and explore Chicago's arts, culture, and architecture. Mark your calendar now. Registration will begin in January 2018.

WMers everywhere join me in sending warmest congratulations to Dr. Steven Treon on his recent appointment to a full professorship at the Harvard Medical School. We also express our thanks to Dr. Treon for devoting his medical career to WM with exceptional determination and dedication. Dr. Treon's promotion to Professor recognizes the importance of his research in Waldenstrom's macroglobulinemia.

On March 17, my wife, Elly, and I, along with IWMF Trustees Dr. Linda Nelson and Dr. Barry Nelson, were invited to join a celebration of promotion at DFCI in Dr. Treon's honor. Photos below are from this special occasion.

Stay well and keep paying it forward!

Carl



At the promotion celebration honoring Professor Steven Treon, from left to right, IWMF Trustee and Webmaster Dr. Barry Nelson, IWMF Trustee Dr. Linda Nelson, Professor Treon, IWMF President Carl Harrington, and Elly Levie.



Carl Harrington congratulates Professor Steven Treon.



The special card created for the occasion by Webmaster Barry Nelson portraying Professor Treon as an IWMF superhero.

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Subcutaneous Rituximab Receives Final US Approval

– The US Food and Drug Administration has approved subcutaneous rituximab (Rituxan) for the treatment of blood cancer patients for whom the intravenous formulation is already approved. The novel formulation includes the molecule hyaluronidase, which facilitates the delivery of rituximab beneath the skin. Subcutaneous rituximab can be administered in 5-7 minutes compared to an hour and a half or more for intravenous administration. The recommendation was based on a review of data from 5 clinical trials which demonstrated that the subcutaneous formulation was not inferior to IV rituximab. The subcutaneous formulation has the trade name Rituxan Hycela.

Letter to Journal *Blood* Discusses Concerns of Ventricular Arrhythmias with Ibrutinib Use

– A letter to the editor of the journal *Blood* from researchers at several centers discussed the incidence of ventricular arrhythmias (VAs) in patients taking ibrutinib (Imbruvica). This retrospective analysis looked at reported clinical trial data of 1,000 patients and identified 10 cases of sudden death or cardiac arrest, which exceeds the expected incidence of such cases in adults in this age range. The authors speculated that one of the kinases inhibited by ibrutinib may be responsible for an increased risk of such events. They concluded that, in randomized trials to date, any increased risk of VAs or sudden death has been outweighed by the benefits of treating the underlying disease; however, it is unknown whether this favorable risk-benefit balance will be maintained as ibrutinib treatment is expanded. In addition, ibrutinib studies currently have short follow-up, and the risk-benefit ratio may change with extended therapy. The authors acknowledged the limitations of their study but suggested that future trials of ibrutinib should be careful to report the incidence of VAs and sudden deaths.

Study Looks at Basis for Acquired Ibrutinib Resistance in WM Patients on Ibrutinib

– A report published in *Blood* looked at the molecular basis for resistance that can develop in WM patients who are on ibrutinib (Imbruvica). This multicenter research sequenced the tumor cells of 6 WM patients who subsequently relapsed after achieving major responses to ibrutinib. Among these patients, 3 had mutations in the ibrutinib-binding gene BTKCys481, with 2 of these patients having multiple mutations. The median time of disease progression in these patients was 16.3 months. Screening of 38 additional patients on ibrutinib without clinical signs of disease progression identified BTKCys481 mutations in 2 patients, both of whom subsequently relapsed. These mutations were not identified in baseline patient samples before treatment or in 100 WM patients who had not been treated with ibrutinib. Of the 5 patients with BTKCys481 mutations, 1 also had a mutation in the PLCγ2

gene, 1 also had a mutation in the CARD11 gene, and 4 also had mutations in the CXCR4 gene.

Novel BTK Inhibitor in Development for Patients Resistant to Ibrutinib

– Meanwhile, the drug company ArQule has received clearance from the US Food and Drug Administration for its Investigational New Drug application to conduct a Phase I clinical trial of ARQ 531 in patients with B-cell malignancies. This trial will include patients who are resistant to ibrutinib (Imbruvica) because of a BTKCys481 mutation, which is emerging as a predominant resistance mechanism. In contrast to ibrutinib, which is an irreversible inhibitor of BTK and binds to it at the Cys481 binding site, ARQ 531 is a reversible inhibitor that does not require interaction with Cys481. The Phase Ia segment of the trial will be open to patients with B-cell malignancies to establish a recommended dose. Upon completion of the Phase Ia segment, the company plans to expand the Phase Ib segment to include patients with a Cys481 mutation who are refractory to other therapies. The trial is expected to begin in the third quarter of 2017.

Analysis Looks at Long-Term Safety of Bendamustine in Previously Treated NHL Patients

– Although bendamustine was approved in 2008 for non-Hodgkin's lymphoma (NHL) by the US Food and Drug Administration, there is only limited information on the long-term safety of the drug. A retrospective analysis published in the *British Journal of Haematology* looked at data from 149 patients who were in 3 earlier studies of the drug and who were followed up for about 9 years. In 2 of the studies, bendamustine was used alone, while the third study used the combination of bendamustine with rituximab. The patients included in the analysis had relapsed or refractory follicular, small lymphocytic, marginal zone, mantle cell, transformed, or lymphoplasmacytic lymphoma and had received a median of 3 therapies before being treated with bendamustine. Of these 149 patients, 23 developed secondary cancers of the skin, colon, prostate and lungs, 6 developed myelodysplastic syndrome (MDS), and 2 developed acute myeloid leukemia (AML). According to the study authors, the rate for MDS/AML was not higher than expected, considering that these patients had been previously treated with drugs that are associated with the development of this complication. Twenty-six infections were also reported after bendamustine therapy but before subsequent therapy; these included sinus and pulmonary infections, herpes simplex virus/varicella zoster virus, blood sepsis, and urinary tract infections. Following bendamustine, stem cell collection was successful in 9 of 12 patients, also an expected result because of other published studies. Median overall survival after bendamustine was 65.9 months – for single agent bendamustine it was 44.9 months and for the combination of

Medical News Roundup, cont. on page 6

bendamustine and rituximab it was 113.2 months.

New Antibody-Drug Conjugate in Early Trials for B-Cell NHL Patients – Pinatuzumab vedotin is an antibody-drug conjugate in which a monoclonal anti-CD22 antibody is chemically bound to a chemotherapy drug called monomethyl auristatin. Results of a Phase I clinical trial using this conjugate in relapsed/refractory B-cell non-Hodgkin's lymphoma (NHL) and chronic lymphocytic leukemia (CLL) were recently reported in *Clinical Cancer Research*. The study determined the appropriate dosing for a Phase II trial and evaluated its safety, tolerability, and activity alone and with rituximab. Seventy-five patients received single-agent pinatuzumab vedotin. Neutropenia (low neutrophils) and peripheral neuropathy were the most common adverse events, and peripheral neuropathy most frequently resulted in treatment discontinuation. Rituximab co-treatment did not impact the safety and tolerability of the drug conjugate. The dosing established for Phase II trials was 2.4 mg/kg. The drug is manufactured by Genentech/Roche.

Early Trial Results Reported for Combination of Ibrutinib with Novel PI3K Inhibitor in CLL – Preliminary results were reported for a multi-center Phase I study of TGR-1202 in combination with ibrutinib (Imbruvica) in patients with relapsed or refractory chronic lymphocytic leukemia (CLL) or mantle cell lymphoma. TGR-1202 is an oral PI3K-delta inhibitor designed to have less toxicity than other PI3K inhibitors (such as idelalisib). A total of 28 patients were able to be evaluated, including 17 CLL patients. The most common toxicities in these CLL patients included diarrhea, nausea, neutropenia (low neutrophils), thrombocytopenia (low platelets), and anemia. CLL patients had an overall response rate of 82%. The study has been expanded, with a recommended Phase Ib and Phase II dosing of 800 mg daily.

Retrospective Study Analyzes Outcomes of Ibrutinib Dose Reduction in CLL – In correspondence to the *British Journal of Haematology*, the Abramson Cancer Center at the University of Pennsylvania published results of a multicenter retrospective analysis to look into the efficacy of dose reduction of ibrutinib (Imbruvica) in chronic lymphocytic leukemia (CLL) patients. The analysis was performed of patients treated at three institutions from 2010-2015. A reduced dose was defined as being below the approved FDA daily dose for longer than 2 months at the beginning of treatment or within 3 months of beginning treatment. Of 197 CLL patients treated with ibrutinib, 37 received a reduced dose. Reasons for dose reduction included gastrointestinal toxicity, bleeding, and the need to adjust for absorption, metabolism, or excretion of the drug. The results indicated an overall response rate of 85% for the standard dose vs. 84% for the reduced dose. Median overall survival was not reached for either the standard or reduced dose, while median progression-free survival was 37.4 months for the standard dose vs. not reached for the reduced dose. The authors

indicated that reducing the dose in CLL patients did not result in a poorer clinical outcome. The authors also suggested that future studies should consider weight-based dosing.

Another Retrospective Study Reports Contrasting Outcomes for Ibrutinib Dose Reduction in CLL/SLL – Another multicenter retrospective study published in the journal *Blood* discussed the impact of intermittent interruption of ibrutinib (Imbruvica) therapy on clinical outcomes in 195 chronic lymphocytic leukemia/small lymphocytic leukemia patients who were enrolled in the Phase III RESONATE study. Intermittent interruption in dosing has been recommended for treatment-related toxicity and invasive procedures. In contrast to results reported from the study above, these investigators suggested that optimal adherence to the recommended ibrutinib dosage was associated with superior patient outcomes, including improved progression-free survival and a trend toward improved overall survival. These authors also stated that the recommended dose should be initiated in all CLL/SLL patients irrespective of weight or age and that sub-therapeutic drug levels may promote resistance to the drug.

New Anti-CD20 Monoclonal Antibody Ublituximab Evaluated in B-Cell NHL and CLL – The monoclonal antibody ublituximab (TG-1101) was evaluated in a multicenter Phase I/II clinical trial that was published in the *British Journal of Haematology*. Ublituximab is a chimeric anti-CD20 antibody that was used in this study in patients with B-cell non-Hodgkin's lymphoma (NHL) or chronic lymphocytic leukemia (CLL) who were relapsed/refractory to rituximab (Rituxan). Following weekly treatment with ublituximab for 2 cycles, patients received monthly maintenance with ublituximab for cycles 3-5 and then once every 3 months for up to 2 years. The most common adverse events were infusion-related reactions, fatigue, fever, and diarrhea. The overall response rate was 45%. Median duration of response was 9.2 months, and progression-free survival was 7.7 months.

Ublituximab Combined with Ibrutinib for High Risk CLL Patients – Meanwhile, TG Therapeutics announced data from its Phase III GENUINE study of ublituximab (TG-1101) in combination with ibrutinib (Imbruvica) in patients with high risk chronic lymphocytic leukemia (CLL). This multicenter study, conducted at 160 clinical trial sites in the US and Israel, included 126 patients. It met its primary endpoint, demonstrating a significant improvement in overall response rate for the combination of TG-1101 + ibrutinib (80%), compared to ibrutinib alone (47%). From a safety standpoint, the combination was well tolerated. The company plans to meet with the US Food and Drug Administration to discuss the filing of data for accelerated approval.

Idelalisib Improves Progression-Free Survival in Relapsed/Refractory CLL Despite Toxicities – Despite significant

toxicities, idelalisib (Zydelig) improved progression-free survival in patients with treatment-resistant chronic lymphocytic leukemia (CLL), according to interim findings of a Phase III study published in *Lancet Oncology*. At a median follow-up of 14 months, progression-free survival was 20.8 months for 207 patients receiving idelalisib vs 11.1 months in the study's control arm of 209 patients. In the idelalisib arm, patients were given the drug in combination with bendamustine plus rituximab, while in the control arm, patients were given placebo in combination with bendamustine plus rituximab. Serious adverse events, including fever, febrile neutropenia (fever with low neutrophils), and pneumonia occurred in

68% of patients administered idelalisib, compared to 44% in the placebo arm. An increased rate of infections has been noted in previous reports of idelalisib treatment, particularly cytomegalovirus infection and *Pneumocystis pneumonia*.

The author gratefully acknowledges the efforts of Peter DeNardis, Wanda Huskins, Pavel Illner, John Paasch, Colin Perrott, Howard Prestwich, Charles Schafer, Ron Ternoway, and others in disseminating news of interest to the IWMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

PROFILE OF A CRYO PATIENT

BY FAY L, AS TOLD TO ALICE RIGINOS, TORCH EDITOR



Fay L., a patient whose life as a severely immuno-compromised WM patient is compounded by the fact that she also suffers from cryoglobulinemia.

When Fay L was diagnosed with WM in August of 2001, her greatest concern was not the diagnosis of cancer. Already a cancer survivor, Fay was then living beyond three previous cancer diagnoses. As she comments, "The diagnosis of yet another cancer did not scare me. The journey was of concern." The "concern" – to continue Fay's term of understatement –

was that her diagnosis of Waldenstrom's macroglobulinemia was complicated by a second extremely rare blood disorder known as cryoglobulinemia.

Fay describes "cryo" from the patient's perspective as follows:

"With cryo, your blood thickens in cold temperatures, presenting its own special set of issues including special handling of the blood, concerns over test results, concerns over the weather and the air temperature. Even the warm climate of Florida (where I now live) presents special problems from cold air conditioning. And, in addition, there is still concern regarding the blood warmer that must be used for plasmapheresis and blood transfusions, not to mention the special concerns of room and body temperature during surgery. Finally, making sure that all health care workers who are part of your team are familiar with your special needs is often very trying."

One stroke of good luck was that Fay found a hematologist experienced in the management of cryoglobulinemia at

Memorial Sloan-Kettering in New York. Her IgM level (3200 at diagnosis) was managed by plasmapheresis at intervals of 3-4 weeks for the next six years. Before retiring in 2006, Fay, a banking consultant in the computer industry, developed a strategy to avoid the difficulties that winters in New Jersey presented to a patient with cryo: she convinced her office to allow her to work out of the Tampa office during the winter months. The next step was to leave the cold northern climate of New Jersey and relocate in Florida when she retired.

In planning for her move south, the most important decision Fay faced was to determine where the patient with cryoglobulinemia would find a doctor with the experience to manage her treatment. She first compiled a list of potential locations and then sought recommendations for hematologists experienced with cryo; a hematologist at the Mayo Clinic in Jacksonville, FL, was high on the suggested list. Fay first interviewed the recommended doctor and found he agreed to continue with periodic plasmapheresis until there was a change in her condition. She then went ahead with her plans to move. This doctor is still managing her treatment today, eleven years later.

At the time Fay relocated in Florida, her IgM level was 6000, and her new doctor determined that the time for treatment had come. He agreed, however, to postpone treatment for another six months until the wedding of Fay's daughter. Treatment with fludarabine and Rituxan followed, a combination that was effective for two years. After this she returned to periodic plasmapheresis until treatment was again required. Fay continues the narrative:

"In late 2011 I required treatment once more, and this time I insisted on putting treatment off until my second grandchild was born. I began Cytosan combined with Rituxan. After several rounds I began to have fevers and became disoriented. It took quite a while to determine that I had developed cytomegalovirus (CMV), a virus seen more often in transplant

Profile of a Cyro Patient, cont. on page 8

patients. I believe I am the only patient at Mayo Clinic Jacksonville to develop CMV after chemotherapy. However, once I had an accurate diagnosis and the proper treatment was given, I had one more year of relatively low IgM, followed by Velcade combined with Rituxan, my most successful treatment to date.

So, with three prior cancers, several cycles of Waldenstrom's treatment, and now increasing occurrences of pneumonia, my oncologist often reminds me that my immune system is severely compromised and that I should take precautions to avoid exposure to infection."

FAY'S TIPS TO MINIMIZE EXPOSURE TO INFECTION

A complication for me is that in retirement I enjoy playing bridge. In this situation, you have players coughing into their hands, picking up cards, and so forth. And when you do not look sick, as is the case for many of us WMers, it becomes more difficult, socially speaking, to enforce precautions among other players at the table. I am not sure exactly when I started wearing a facemask, but – as I explained to my bridge companions – the risk of infection was the driving force.

Today I wear the flimsy accordion-type facemask when I play cards. I carry them with me at all times. If I am out and about and there are coughers and sneezers around who are irresponsible, then I whip out a facemask. Unfortunately, the mask does not seem to intimidate those irresponsible coughers and sneezers, as I initially thought it might. Some people actually think I wear a mask to prevent others from getting my illness. Others just don't care.

When I fly, I wear the formed blue facemasks that the transplant patients wear. Short flights are not a problem. On long flights, if you need to eat and hence take off the mask, I think you should probably not even bother wearing it.

As a result of all my treatments (and the lack of awareness of the general public to our concerns) I have adopted some routine habits in the attempt to minimize my exposure to unwanted organisms. Some may think these are extreme, but they seem to have helped me. Many are obvious, but there is no harm in being reminded. I am happy to share my protective habits with *Torch* readers!

EVERYDAY CONCERNS

- I do not touch door handles used by the public. I use the handicapped buttons, which I push using the side of my body. Or I wait for someone to open the door, and then I follow that person in. If this strategy fails, I wrap my clothing (a jacket or scarf, for example) around the door handle before using it. In the bathroom I also use paper towels when they are available.
- I use my knuckles to push elevator buttons.
- I also use my knuckles to use an ATM machine. I was waiting for an ATM when I saw a customer coughing and sneezing

over the input area. To be sure, it is more difficult to punch a key with the knuckles than a finger, but it will work.

- I never pick up pencils or a pen used by the general public. If I have to sign my name on a credit card slip or sign to process a charge on a debit/credit machine, I ask for a tissue to touch the implement. If that is not available, I ask the clerk to scribble my name. (I could carry my own pencils but I usually lose them.) If all else fails, I have hand cleaner with me at all times.
- Be aware of what is around you. When I am in line to pay, if the clerk is coughing into his or her hands (which happens more frequently than you would think), or touching the face, or playing with his or her hair, I ask for someone else to wait on me. You can expect snickers and comments, but this is your life.
- Often I am told that the coughing and sneezing of others is only from an allergy. I usually comment that if the coughs and sneezes are germ-free, then there is a perfect topic for a dissertation. After people get to know me, I find it interesting that they no longer cough near me. But, if they sit with someone else, then they cough . . . more of a nervous habit.
- When I need an elevator, I often wait for a less crowded one. One thing I do have is time.

EATING OUT

- Menus are loaded with germs. I carry small bottles of antibacterial cleaner with me at all times and use it after I have read the menu.
- The cloths used to wipe the tables look to be full of germs. I try to prevent utensils from touching the table by keeping them wrapped in the napkin until the food is served. Then I rest the utensils on the plate.
- I skip buffets. If buffet-style is unavoidable, you can make do with breakfast by requesting individual boxes of cereal or containers of yogurt. I also ask if I can have food brought to me from the kitchen before it is brought out to the general public to breathe and pick over.
- Skip the salad bar for obvious reasons.
- Request a booth. Sitting in a booth offers more protection and is better than having someone at the next table coughing and sneezing away.
- When I accept an invitation to a luncheon or dinner meeting, I ask if I can get my food before it is open to the group. There has never been a problem with honoring my request. Sometimes those with health issues are called up first to the table. Often I find that I am not the only one in these circumstances.

My suggestions may seem cumbersome, but they have become second nature to me.

And I see a difference!!!!

IWMF CONNECT: SPRING 2017

BY JACOB WEINTRAUB, MD

The IWMF Ed Forum, held this year in Phoenix, again proved to be a significant event for learning, questioning, meeting old friends and making new friends. For coverage of the 2017 Ed Forum, go to iwmf.com and see pages 14-19 of this issue. Meanwhile, discussions continued online. The online discussion group recently underwent some changes and has a new name: IWMF Connect. By now most of us have adapted to the changes. Some people think the new format is much better, some think it is much worse, and most of us are managing well. There are articles posted on all subjects from “enjoying the moment” to the lighter side of cancer. Discussions are ongoing about fatigue and returning to work after diagnosis, about palpitations and atrial fibrillation, and other topics.

HUMAN INTEREST/ARTICLES

Wanda H posted links to several items of interest.

This article, titled “The Lighter Side of Cancer,” is from *Cure Today*. The author is Kevin Berry, an 11-year survivor of mantle cell lymphoma who was undergoing his third bone marrow transplant. He relates one humorous incident and tells other jokes. The article definitely gives us a different perspective on cancer.

<http://pgj.cc/zBARE8>

Another post from Wanda is to an article with the title “In for the Long Haul.” This is an article about caregiving for a person whose cancer becomes a chronic condition. Here, the patient has multiple myeloma, a cancer that “will never go away,” an issue to which we all can relate.

<http://www.cancertodaymag.org/Spring2017/pages/In-For-The-Long-Haul-Caregiving-Over-Time.aspx>

One more post from Wanda is about strategies for pacing ourselves when we are sick or in pain. The article talks about giving one’s own self permission to slow down. This advice is especially relevant in view of a discussion online about the ability to return to work after diagnosis.

<http://www.kevinmd.com/blog/2017/04/5-effective-strategies-pacing-youre-sick-pain.html>

Karen R then posted that, following the links in this article, she found other books by the same author, at least a couple of which could be very helpful for us Wallies living with chronic disease.

IWMF Connect Manager and IWMF Trustee **Peter DeNardis** posted a link to an article in *Lymphoma News Today* presenting a nice summary of some of the emotions many of us have gone through when first diagnosed and afterwards: “10 Common Emotional Responses to a Cancer Diagnosis.”

<https://lymphomanewstoday.com/2017/04/28/feelings-and-cancer>

Of note are the multiple links within this article, leading the reader to other articles, most of which have been topics discussed on IWMF-Talk and IWMF Connect.

One additional post from Peter is a link to an article about a singing oncologist who uses music to show patients “A Little More Love.” The feelings expressed toward his patients by this oncologist are very impressive. How many of us have had someone write a song for us, let alone a song written by a physician?

<http://tinyurl.com/singingdoc>

A companion piece posted by Wanda is a short video from BBC News about an artist who draws sketches of cancer patients during appointments or during the time they may be receiving chemo or other treatment. The reaction of the patient in the video is priceless.

<http://www.bbc.com/news/health-39577218>

RETURNING TO WORK

Andrea V asked the group about returning to work post-diagnosis. She was diagnosed in 2007 and works in a hospital in a demanding job. She wanted to know what experiences people have had in returning to work.

David P reported that he is an environmental lawyer whose workload has increased significantly recently. He was diagnosed in 2010 and has not missed a day of work due to his WM except for time off for doctor visits and other medical issues. His suggestion was to keep a positive attitude and “kick butt.”

Liane C reported that she teaches college biology. She was off one semester so she could deal with a stem cell transplant and all of the associated appointments. She was very sick when diagnosed but never missed a day of classes. She returned to work two months after her transplant and regularly does 10-hour days and more. She has been hospitalized for “this and that” but has been back to work “in no time.”

However, **Pat G** wrote she had to stop working several years ago due to recurrent infections. She still gets infections, seemingly more serious now than before. She notes some recommendations from others would not work for her because, she reminds us, “we are all so different.”

Julie T also notes difficulty with working. She has been treated, but her fatigue level prevents her from doing anything physically demanding for more than a short time. She can mow her tiny back yard but takes a break before blowing off the clippings. She takes daily walks but has to rest before doing anything else. Julie also notes that she has both WM and multiple sclerosis.

IWMF Connect, cont. on page 10

Pete S reported that he was on a clinical trial at Dana Farber 20 months ago but kept up his work as a solar installer and designer throughout. He still was able to ski and kayak and mountain bike. However, recently he experienced fluid in his left lung that needed to be drained. He also has noted a decrease in his respiratory function. This has limited his activities somewhat, but he still was able to go for a light jog recently. He suggested that each person's body makes its views known: respect what our body tells us about limitations but stay engaged and smile.

Finally, **Susan F** posted that she is a public school teacher and has missed about two days since her relapse in 10/2016. She takes ibrutinib and finds herself very sleepy in the evenings. Susan has made adjustments to her schedule and hopes the fatigue will improve over summer vacation.

TINNITUS

Ringing in the ears is a topic that is discussed periodically. Pulsatile tinnitus, though somewhat different, does also occur and has generated some discussion.

Andi S referenced a website with a description of pulsatile tinnitus (whooshers.com). The question then was posed if there is any correlation to WM? If someone has been diagnosed with pulsatile tinnitus, who made the diagnosis? Was it an ENT doctor? Vascular doctor? Possibly a neurologist?

Dr. Tom Hoffmann responded that pulsatile tinnitus is a pulsating noise in the ear, and he suggested that the most important thing to do is to have tests to be sure the noise is not produced by blood turbulence from a blockage in the carotid artery.

Marilyn T reported she did have a whooshing tinnitus prior to her treatment for WM. The noise was not constant and was only in her right ear. It was triggered by sounds like running water. At first it was occasional, then gradually increased in frequency and duration. It still was intermittent, so it was annoying but not debilitating. She then needed treatment with bendamustine and Rituxan. When her IgM declined significantly, the whooshing stopped. She has attributed this phenomenon to her WM and has not had a formal evaluation or diagnosis.

John R had a similar experience. He experienced a whooshing sound along with a tightening feeling in his head every day for a few years prior to WM diagnosis. When it was mentioned to the primary care doctor, there was no understanding at all. Finally an ENT doctor explained what it is and how rare it is. It only seems to happen in periods of stress and fatigue. John still thinks it is related to WM.

There also were some posts in this discussion about general tinnitus.

Julie T reported that she awoke one morning because she heard a big truck idling outside the house where she was staying with friends. She finally realized that every time

she made any kind of noise, the truck quit making noise for a brief second or two. Then she realized there was no truck! This noise persisted intermittently for several years and disappeared after she was diagnosed with WM and treated. She heard the noise only when she was in a quiet environment, for example when she was trying to go to sleep. She also realized that the sound went away when her IgM decreased after treatment. Now her IgM has risen nearly to its level at the time of diagnosis, and the "truck in the distance" noise has returned. Julie suspects that an elevated viscosity is causing the noise, and she will monitor her blood in an attempt to correlate viscosity with the noise she is hearing.

Barb H also reported having the sound of heavy equipment in her ears. She was evaluated by an ENT doctor and was found to have a moderate hearing loss in both ears, along with low frequency tinnitus. She has been followed by the specialist and has had an ear tube placed in her left ear due to infection. The noise has diminished but has not gone away completely. The noise has also affected her sleep, but at least her doctors are aware of it and are monitoring her ear status.

PALPITATIONS

Pete S asked if anyone with WM and not on Imbruvica has suffered palpitations for an extended period of time and if a doctor suggested a connection between the palpitations and other causes like anemia, decline in hemoglobin, or enlarged spleen?

Jim D posted a comment about atrial fibrillation with palpitations that could lead to fainting (or worse).

Dr. Tom Hoffmann answered that any assertion about heart stopping due to palpitations and atrial fibrillation is not valid. Palpitations simply mean that a person can feel his or her heart beating, and this could be from a normal heart when the person is under stress. Palpitations have no prognostic implication in atrial fibrillation. Of greater concern is silent atrial fibrillation or another arrhythmia that a person cannot feel and so does not realize that help is needed.

Leslie H thanked Tom for the clarification. Leslie has experienced palpitations and the feeling is that of being uncomfortable, not physically so much as psychologically. Leslie does not like feeling her heart beat all the time. An extra beat is felt occasionally, and she has been taking a beta blocker for 40 years and this helps keep a slowed rate with fewer palpitations.

Finally, **Fred B** posted that he went to his cardiologist recently. The cardiologist took Fred off anti-arrhythmic meds because the cardiologist said that the meds "were not doing anything and can have side effects." He was more worried about the heart rate. Fred, too, now is taking only beta blockers. The cardiologist feels that ablation or cardioversion would not work since the fibrillation is being caused by ibrutinib. Fred

also is not taking anticoagulants except for aspirin because his platelet count is low and his doctor thinks Fred is at low risk for stroke.

Finally, IWMF Connect learned of the death of a long-time participant, **Lou Birenbaum**. Lou was diagnosed before 1998 and later was diagnosed with a second blood cancer, possibly CLL. Lou was one of the initial handful of members on the IWMF-Talk forum when it first began and was a frequent contributor. He had a great sense of humor and was

a big help to many on IWMF-Talk, especially with respect to Cytosan. He will be missed in this forum.

As always, there is a much wider range of topics and discussions than can be presented in this limited space. You are all invited to join and just “listen” or participate. If you have any discussion topics that you are particularly interested in, please let me know and I will try to include those discussions in a future column. I wish you all good health.

IWMF CONNECT – CONNECT ONLINE WITH FELLOW WMERS

BY PETER DeNARDIS, IWMF TRUSTEE AND IWMF CONNECT MANAGER

Since the early days of the IWMF, there has been an online email-based group discussion forum in English, IWMF-Talk, which has allowed patients and caregivers to share experiences and insights, exchange information, and give and receive emotional support.

The discussions typically have focused on WM diagnosis, treatments, research, prognosis, side effects, and related conditions. Other important information has been conveyed about patient advocacy, outreach to doctors, concerns of the newly diagnosed, and information about the IWMF’s member services and research activities.

IWMF-Talk was initiated over 20 years ago, in the early days of the Internet when online communications occurred primarily via email messages and has remained in that mode since. Today, significant advances in technology have brought about newer and more user-friendly means of communicating online – tools such as online discussion boards and social media like Facebook and Twitter.

Over the past several months, a cross-section team of IWMF Board members and select WM patients and caregivers

worked together to determine the more common topics of interest, test a new system using current technologies, and arrive at an end product that would best meet the needs of the entire WM community.

The IWMF is now prepared to take advantage of the newer technologies and has launched a new version of the discussion list, called IWMF Connect. Patients and caregivers can still communicate with each other but in a manner that allows for topic-based discussions and more targeted conversations. Interactions and discussions will take place via the discussion board that you’ll find once you access IWMF Connect.

With IWMF Connect, you will have a much easier way to search for postings about topics that are of special concern (like “ibrutinib” or “IVIg,” for example) and a much easier way to manage your own subscription.

Why not join us on IWMF Connect? To read more about it, and to join, go to: <https://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums>

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



IWMF DOC STAR: JEFFREY MATOUS, MD

EDITED BY RON TERNOWAY



Marie and Jeff Matous visiting the Taj Mahal.

“He is really focused on knowing the whole family, the whole person, and keeping up with us year after year. He is a great listener, a positive champion, extremely knowledgeable – we all just *love* him as a doctor!”

These are the words of Cindy Furst, IWMF Support Group Leader for Colorado, South Wyoming, and New Mexico. The “he” in question is Dr. Jeffrey Matous, Medical Director at the Colorado Blood Cancer Institute (CBCI) in Denver and Clinical Professor of Medicine at the University of Colorado.

Cindy elaborates that Dr. Matous is the one frequently suggesting meetings: “We really should talk to ‘Team WM’ (that’s what he calls us) about what we learned in Amsterdam! Or wherever the last big meeting was. He comes out two or three times year on a Saturday to talk to us.”

But for author Albert Camus and a cataclysmic world event some four decades ago, Dr. Jeffrey Matous might today be Ambassador Jeffrey Matous and the world of hematology deprived of a true Doc Star.

Matous grew up in Seattle, Washington, the third of six children of an FBI agent and a “brilliant” stay-at-home mom. At the University of Washington he pursued a liberal arts education, primarily in languages, majoring in French. He also studied German, Spanish, and even Persian, planning to use language to become a diplomat or an international “something or another.”

In 1978 his parents and three youngest siblings moved to Teheran, Iran, for work matters. Jeffrey’s plans to join them were brought to an abrupt halt by the Iranian revolution, which deposed the Shah, established the Islamic Republic of Iran, and sent his family scurrying safely home to America.

Deprived of the opportunity to go to Iran, and after spending most of his academic career delving into French literature, he

heard the words of Dr. Rieux from Camus’ *The Plague* and looked for a way to become “engaged.” He promptly changed his major and decided to become a physician.

At the University of Washington Medical School, all of his role models were hematologists. After graduation he trained in Internal Medicine at the University of Colorado, where he met and married Marie Sweeney, “the love of my life.”

Upon completion of his fellowship in Hematology and Bone Marrow Transplantation back in Seattle, where he worked with one of the greats in contemporary hematology, Dr. Ken Kaushansky, he set up a private practice in Denver in 1994, focusing on the care of patients with blood cancers. “We have a unique setup at CBCI,” he says. “We are a private practice group that provides top quality academic medicine. My physician colleagues and staff have a passion for caring for patients with blood cancers and advancing better care through research.”

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). In 2012 he was honored with the Chairman’s citation for LLS volunteerism and in 2017 with the LLS John J. Kenney Award.

So how does one human dynamo satisfy the needs of dozens of blood cancer patients, *and* find time for work-life balance? Here’s what the good doctor says:

“I have become so busy that I do not get to spend enough time with all of my patients. I rely heavily on my colleagues, and especially Megan Andersen NP, who has been my right hand for so many years.

“My family is my major source of work life balance – my wife of 30 years Marie, my sons Ben and Joe, and my daughter Catherine. I have wonderful siblings and we are close in all ways but geographically. Outside of work I love to ride my bicycle, attend Colorado Rockies and Denver Bronco games, and still pursue my love of languages. I have learned some Italian and read French with regularity.”

Dr. Matous has written articles for the IWMF *Torch*, notably the September 2016 Doctor on Call article on ibrutinib. He has presented at three IWMF Educational Forums, including the most recent one in Phoenix, where he spoke about *The ABCs of WM* and co-moderated a breakout session on ibrutinib.

COOKS' HAPPY HOUR

BY PENNI WISNER

My favorite restaurant in San Francisco recently published a cookbook: *Nopalito, A Mexican Kitchen* by Gonzalo Guzmán with Stacy Adimando (Ten Speed Press, 2017). Nopalito is not a burrito parlor, but the menu is small and fairly simple. Food so simple and so direct depends on great quality ingredients carefully prepared. That does not mean difficult to prepare. Here's the chef describing the food: "At Nopalito we do home-style, authentic Mexican food with seasonal, organic ingredients, giving the dishes fresh and delicious twists in line with today's ever-evolving food world."

Am I gushing? I haven't even warmed up yet! My partner and I have been going there since the restaurant opened in 2009. Every time (and we went weekly for a long time), the food impresses me again. The flavors are direct, clean, fresh, immediate. There are dishes we love so much we order them every time: the lettuce salad and the ceviche. The salad combines little gem lettuces with thinly sliced apples and radishes, avocado, spicy peanuts, some tortillas cut into matchsticks and fried, a shower of shaved ricotta salata, and a dressing that combines a smoked jalapeño with lime juice, salt, apple cider vinegar, and an equal mix of rice bran oil and olive oil. Lucky for us here in the city, we can buy the dressing by the bottle. We've not yet been successful at the jalapeño smoking. But you can burr up a fresh or roasted one with the rest of the dressing ingredients. The dressing is not really spicy just wonderfully tasty. Try it!

Ah, yes, finally I get to the meat of the matter: fish and seafood. There is little better food for hot weather than ceviche. (The American version would be crab and/or shrimp cocktails with their spicy tomato-horseradish dipping sauces.) For ceviche, raw seafood marinates in seasoned lime juice until "cooked." But it still will not be the same as if broiled or sautéed. If you are concerned about eating raw seafood, ceviche may not be for you. For the same reason, if you do make ceviche, you must buy the very best quality you can find. Both these recipes use shrimp and the preferred type is the white Gulf variety. Plan to make your ceviche just before serving. Too much time in the lime juice and your seafood may turn rubbery.

This ceviche version can be made any time of year. To serve six as an appetizer or snack (with your favorite margarita or Mexican beer!), combine 1 pound fresh shrimp, peeled, deveined, and cut into small pieces with 1 cup fresh lime juice,

about ¼ cup finely chopped red onion and 1 ¾ teaspoons kosher salt in a ceramic or glass bowl. Stir well and let sit ten minutes, stirring occasionally. Add ½ cup grated carrots, ½ cup finely diced cucumber, 1 to 3 finely chopped serrano or jalapeño chiles, ¼ cup roughly chopped cilantro, 1 thinly sliced green onion, and stir again. Season to taste with more salt and lime juice. Just before serving drizzle with a little olive oil. Serve immediately with crisp, salty tortilla chips. And serve with spoons: you will want to drink all the juice left in the bottom of the bowl.

Since it is summer and tomatoes with flavor (finally!) are available, try this shrimp and crab ceviche with tomatoes, onions, and jalapeños: Put 2 tablespoons fresh lime juice in a small pan of water, season well with salt, and bring to a boil. Add 2 cups chopped shrimp (about 1 ½ pounds shelled, deveined shrimp) and cook just until pink and opaque, 30 seconds or so. Do not overcook! Drain immediately and spread out to cool and then chill. You can cook the shrimp up to 2 days ahead (but this does not seem such a good idea to me). Store well wrapped in the refrigerator. When ready to serve, combine ½ of a small white onion, finely chopped, with 1 cup fresh lime juice in a medium bowl. Let sit 5 minutes. Add the cooked shrimp, 1 cup cooked and chilled fresh crabmeat, 2 finely chopped jalapeños, and ½ bunch roughly chopped cilantro. Toss together well and let sit another very few minutes. Just before serving, stir in 2 cups halved small cherry tomatoes or garden ripe heirloom tomatoes. Toss again and taste for salt and lime juice. Serve with chips (as always!).

The book includes a halibut ceviche with árbol and guajillo chiles plus lime, red onion, jalapeño, cilantro, and avocado. And yet another with squid, cod, and fresh tomatillos. Then there are recipes for the addictive snack, fried chickpeas with chili powder. And I am very happy to say the book includes the recipe for the restaurant's Mexican Wedding cookies. Chef Guzmán said the cookies are no longer served because too many returned to the kitchen. What is wrong with people?! I would have happily adopted all those unwanted cookies. But now I have the recipe so the world has righted itself for now. I guess the easiest thing would be for you to buy the book, but you can get a taste for it here first.

Our motto: Eat Well to Stay Well

“A BIG FAMILY REUNION”

AN IWMF STAFF PERSPECTIVE ON THE 2017 ED FORUM

WRITTEN BY RIKKI MILLER, AS RECOUNTED BY JENNIFER SILVA



When Jenifer Silva was hired as Operations Manager of the IWMF in February of this year, plans for the 2017 IWMF Educational Forum were in place. The Phoenix Renaissance Downtown Hotel was under contract, and the Ed Forum Committee already had commitments from the invited speakers. Clearly, Ed Forum 2017 was going to be a learning experience for the new Operations Manager. As May 19 drew closer, the Torch issued a call for a volunteer to write a post-Forum article for the newsletter. Jennifer responded at once: she volunteered to write an article from the double perspective of a member of the IWMF office staff and a “first-timer” as well. The final article below is the result of a collaborative effort between Jennifer and Rikki Miller, IWMF Development Manager, who also attended the Phoenix Ed Forum.

This report from Jennifer and Rikki captures “with fresh eyes” the intensity and, yes, excitement of an Ed Forum from the perspective of staff members. This is not a report to cover the scientific content of the presentations from WM experts delivered Friday-Sunday. Rather, Jennifer and Rikki capture the spirit of the three-day event known as the Ed Forum and make very clear that, just as volunteerism created the IWMF, today volunteerism powers the drive to raise funding for new undertakings, to expand services, to increase research, to achieve better treatments and a cure for Waldenström’s macroglobulinemia.

* * * * *

It was 7 am Thursday morning – 10 am where I’m from, which would have helped if my internal clock hadn’t also been off for bedtime the night before. We were in a “pre-con” meeting at the Phoenix Renaissance, Sara McKinnie and the 2017 Ed Forum Committee on one side of the table, the hotel staff on the other.

The hotel-sponsored mimosas weren’t quite breaking the ice, so IWMF President Carl Harrington did.

“I bet when you first heard that you had a bunch of old folks coming with an incurable blood cancer with a name you couldn’t pronounce, your first two thoughts were:

- Boy that doesn’t sound like fun.

- I wonder if I can get out of it.

Well, that was pretty much our reaction when we were all diagnosed.

But we’re all glad to be here and we hope you’ll enjoy our visit. This is our 22nd Ed Forum.

My counterparts across the table and I laugh, maybe too loudly. I’ve been blessed with good health, but not the ability to respond to jokes like this with something witty or less anxious. In truth, I didn’t know much more about what to expect than the conference staff.



Jennifer Silva and Rikki Miller at their post in the registration area during Ed Forum 2017.

Although we work with WMers on a daily basis, most of our communications are done via phone or email. Rarely do we meet people with this disease face to face. Our Sarasota office is compact, with only a few visitors each quarter, often vacationers sweet enough to take some time off from the famous white-sand beaches down the road just to say hello - happy, tan people who seem as distant from that very specific image of cancer patient as the palms outside are from snow. The energy levels of the Board members we work with do not hint at illness. Aside from the occasionally rescheduled

“A Big Family Reunion”, cont. on page 15

call, they don't seem to take days off. It's difficult to imagine that most are battling a disease called Waldenström's macroglobulinemia, in addition to volunteering to meet the needs of this rapidly growing organization.

So, I didn't know what to expect. What I ultimately encountered was a group of vivacious, kind, and unusually accomplished people, a group who handled the early mornings and late nights of those 12-hour plus days with enviable energy and enthusiasm.

Sara McKinnie, the staffer who has been at the IWMF since its very beginning and now works as our events coordinator, describes the Ed Forum "a big family reunion – and, for the first-timers, a big family reunion with a family they didn't know they had!" Sara's right. That's exactly how the Ed Forum felt, like a big joyous reunion. It was a reunion that I'm grateful to have been a part of and one I hope to share with you here.

Thursday: Support Group Leader Workshop

After our pre-con meeting and brief tour of the conference area, it was off to the Support Group Leader Workshop: Support group leaders who come to the Ed Forum a day early participate in a special workshop led by Board Member Marcia Klepac where they share ideas and scheme new ways to make their groups better, more valuable, and more accessible to members, whether in Indiana or India (and yes: representatives attended from both).

Friday: Ed Forum Day 1

Although attendees were filtering in on Thursday evening, Friday was the official kick off. Fortunately, we had a fantastic group of volunteers – Lu Kleppinger, Nancy Hess, Kitty Bushey, Laurie Rude-Betts, Joyce Massoth, Eileen Kratish, Tish Davis, Charlie Koch, Jim Reed, Eileen Carmody, Jay Rothman, Elly Levie, Jane Hendrickson, Cheryl Frustieri, Christopher Rawlings, Ron Ternoway, Zorine Reitzin-Hall, Jay Rothman, and several others who offered to pitch in on the spot – a group which continued to grow even as we were packing up on Sunday. These people are the best – seriously.

The week leading up to the Ed Forum was pure madness in the office – everyone flying around, clutching tracking numbers, praying that everything will make it into the right hands in Phoenix. That everything will come together in a place most of us haven't actually seen yet. By the time we got to Phoenix, those shrill anxieties had reached a fever pitch – when we were greeted by so many friendly and enthusiastic and, in most cases, experienced, helpers, it was such a relief.

Friday started with an early bird session for first timers. Although pitched as an opportunity for newly diagnosed patients to learn more about the basics of WM from a doctor and patient perspective, as a "newbie" myself, I certainly found it helpful!

Ed Forum 2017 officially opened when President Carl Harrington welcomed attendees, and the formal presentations

began, following a program that stretched from Friday morning to Sunday noon. At last I had a chance to meet some of the celebrities of our own: the researchers and physicians. The rock stars of WM are people whose names we hear so often and spoken with such admiration that it's hard not to feel a little intimidated with first meeting Drs. Kyle, Treon, Matous, Gertz, Hunter, Dhodapkar, Ansell (well, okay, we in the office do work more with Drs. Ansell and Kyle since they are on the Board, so I knew in advance what gentlemen they both are!). I had the opportunity to talk with some of our presenters more than others – everyone was in high demand, and seemingly happy to chat with anyone who approached them. These very busy professionals all volunteered their time to come to Phoenix, and their willingness to "talk shop" above and beyond formal presentations certainly exceeded my expectations.

Breakout sessions followed, covering a good range of topics, including financial and insurance issues, Part I of a caregiver session designed to span breakout sessions Friday and Saturday, ibrutinib, and understanding blood tests.

Afterwards, we headed outside to enjoy cocktails by the pool at a sunset reception. As the sky finally started to darken, we went back in for the Welcome Dinner – the most formal event of the weekend, and one I think many will remember as the most moving.



Meghan Gutierrez, the CEO of the Lymphoma Research Foundation, opened Friday evening's program. Meghan was introduced by Carl as his "mentor and friend" whose guidance and collaboration has supported the IWMF in fulfilling its mission.

The formal program began when Carl introduced Meghan Gutierrez, the CEO of the Lymphoma Research Foundation, reminding us that the LRF is the nation's largest non-profit organization devoted exclusively to funding innovative lymphoma research and providing people with lymphoma ("that's you and me," as Carl reminded the audience) and healthcare professionals with up-to-date information about this type of cancer. LRF's mission is to eradicate lymphoma and serve those touched by this disease. Meghan was introduced by Carl as a mentor and friend whose guidance and whose collaboration has greatly helped the IWMF better fulfill our mission and who has always been ready with good

"A Big Family Reunion", cont. on page 16

advice when he has sought direction as IWMF President. In her remarks, Meghan confirmed that this collaboration was important for the LRF as well. She ended with an African proverb that captures the essence of the IWMF-LRF partnership: "If you want to go fast, go alone. If you want to go far, go together." With the partners like the LRF, we will go far.

Carl then returned to the stage as a stand-in for President Emerita Judith May, who was present but recovering from a foot injury that kept her from ascending to the podium. Carl shared that this year's nominee for the Judith May Volunteer of the Year Award had requested that we instead offer a Lifetime Achievement Award in memory of Ron Yee who passed away in November of 2015. The nominee chose to remain anonymous because "Ron is still a powerful inspiration" to the awardee who feels that it was his way of "thanking Ron for teaching me what service means." This was a request that the award committee, many members of which had known and worked with Ron, were more than happy to honor. (Read the words of Carl describing Ron's service to the IWMF and others on page 32.

After a day filled with much optimism and excitement, it would be easy, as a non-WMer, to imagine that those who are leading full lives with the disease are leading secure lives. At this point of the evening I think that the seriousness of WM, the stakes, really sank in again.



Elizabeth Yee (at the left) and Pook Yee accept the Lifetime Achievement Award presented posthumously by President Harrington to Ron Yee for his years of extraordinary service as Trustee of the IWMF.

Carl and Board Member Peter DeNardis showed a series of photos of Ron and shared their memories of Ron volunteering in many roles for the IWMF and spreading his generosity of spirit (or so we could imagine) to everyone he ever met. Carl then invited those members of Ron Yee's family who were present to join him on the stage. Ron's wife and daughter, Pook Yee and Elizabeth Yee, stepped forward to accept the Lifetime Achievement Award in Ron's memory. Elizabeth

spoke on behalf of all the family, including her absent brother and sister, and provided a deeply moving reflection on the father she remembered, Ron with that kind and generous smile evident in all his photos, his compassion, his brilliance, the fullness of his life. She told how Ron had provided homes for all of his children as they grew up, Elizabeth included, doing much of the work by himself, wiring and everything. He was that kind of father, she said. That kind of person.

"He didn't die from this disease. It was important to him that people know this," Elizabeth said in conclusion. "To know that Waldenstrom's hadn't won. And that his work with other members of the IWMF had meant something, for himself and for so many others."

Over the weekend in Phoenix, we heard repeatedly that the prognosis for those diagnosed with WM had improved significantly over the past decade. This improvement did not come about by chance. It happened because WMers banded together and worked hard to distribute information, create research opportunities that would not otherwise exist, and empower patients and care-partners to become their own advocates. At the core of those efforts are remarkable individuals like Ron. Volunteers who spend their early mornings, their evenings, their weekends working to make it all come together.

The other staffers and I are often asked why we do what we do – why IWMF? Why make this your career, this exceedingly rare disease? I know I speak for many of us when I say that it's because of people like Ron - people whose lives are a testament of one person's ability to make the kind of lasting Good we all hope to contribute to the world. We may not have children to build homes for (or the skills to build those homes) but it's a privilege to be able to work in a position where we can be helpful to people who do so much to support one another.

As the evening drew to a close, Carl announced that this year, we were borrowing a ceremony from the International Workshop on Waldenstrom's Macroglobulinemia held in Amsterdam last year. Everyone was invited to come light a candle in honor or in memory of someone special to them. It was a moving end to the evening.

Saturday: Ed Forum Day 2

The day began with a new breakfast arrangement where tables were organized by topics in order to attract others with common interests. The topics included Caregivers, IWMF Connect, Newly Diagnosed, Watch & Wait, and Young WMers. At each table a designated a volunteer was present to lead the conversation.

During lunch on this second morning of the Forum, officers of the IWMF Board delivered their annual reports to the membership. The speakers were Beverly Docteur, recently appointed Secretary/Treasurer; Michael Sesnowitz, Vice

"A Big Family Reunion", cont. on page 18





On Sunday morning the Walkers for Waldenstrom's gathered for a photo opportunity beside the massive panda statue at the Japanese Friendship Garden in downtown Phoenix.

President for Fundraising; Elena Malunis, Vice President for Member Services; and Dr. Guy Sherwood, Vice President for Research. The overall picture presented by the officers was of an organization that is growing on all fronts – more money (2016 was a record year for fundraising), more support groups, more international affiliates (for example, the new Scandinavian group), more requests for proposals and research grants, and more office staff to take on the additional workflow.

Luncheon formalities concluded with the introduction of new members of the Ben Rude Heritage Society. The Society recognizes those IWMF members who have made a commitment to the IWMF by providing legacy gifts. (Read more about the Ben Rude Heritage Society and see the new members recognized this year on page 20). Laurie Rude-Betts, the wife of Ben Rude, the IWMF's second President, welcomed the new members into the Society and presented each with an award to commemorate the occasion.

"A Big Family Reunion", cont. on page 19

I can't think of a more wonderful person to be the face of this Society than Laurie Rude, and not just because the Society was established in memory of her late husband and second IWMF President Ben Rude. Laurie's compassion and her dedication as a volunteer are contagious, as I saw over the full three days of the Forum. No task was too small or too menial for her to take on with enthusiasm - whether it was joining the assembly line of volunteers who spent hours putting together packets for Ed Forum attendees, or running out to pick up extra copies of presentations (as she did just minutes before the lunch presentations started!), Laurie was always there to pitch in - and if she was sitting down, it was almost always behind a booth. She's just one of those people who can't seem to help themselves from doing whatever they can in the moment to pitch in. Her leadership for the Society pays off - this year Laurie announced almost two million dollars in new commitments to the Ben Rude Heritage Society, from nine new families, including two who joined at the Ed Forum.

After lunch it was back to business with sessions resuming on clinical trials considered from the perspective of both patient and medical professional, self-care on the WM journey, and the IWMF-LLS Strategic Research Roadmap.

Sunday: Ed Forum Day 3

Any benefit we East-coasters may have gained from the time switch was definitely gone by Sunday. Still, by quarter after six in the morning, at least fifty of us had gathered in the hotel lobby for the Walk For Waldenstrom's, hoping to beat the worst of the heat.

The Walk For Waldenstrom's was an idea developed by Peter DeNardis: to have a charity 5K walk that everybody could participate in, with one central group of walkers in Phoenix and "teams" all over the country, many led by a support group leader. Because this was the first time that "fundraising live" had been tried at an Ed Forum, no one really knew what to expect or even if the idea would catch on. To our delight, by Saturday evening the first annual Walk For Waldenstrom's was within striking distance of its \$20,000 goal. It was fun to see so many people getting into the team spirit, sporting their Walk For Waldenstrom's shirts. There was an outpouring of "offline" support from many attendees, including some who created teams on the spot.

The Waldenström Walkers were a cross-section of those attending, including Board members and even some speakers and researchers (thanks for your support, Dr. Treon!). At 6:30 all left the lobby to head out on a route that led up the street and through a park adjacent to the Japanese Friendship Garden, where we visited the massive panda statue for a photo opportunity. It was a quiet morning, and hot, but not distressingly so - ultimately the Walk made for a nice opportunity when walkers could reflect with each other on the weekend which, in a few hours, would come to a close.

After returning just in a time for a quick shower, the Waldenström Walkers went for breakfast. All the while my colleagues and I were busy gathering and tallying up donations to the Walk for the final announcement that Carl made after breakfast. We exceeded our \$20,000 goal! What's more, even since that morning we have continued to receive additional gifts, for which we are very, very grateful! I think we all agree that this was the start of a fantastic new tradition.

The final hours of the Ed Forum were a bit of a blur. While most of the attendees were in the "Ask the Doctor" session (one so popular that we were having to turn down additional questions even as it started), our team began the bittersweet process of saying our goodbyes and packing up.

A final note: the Renaissance Hotel staff was consistently wonderful, particularly those from food and beverage. As anyone who has worked in event planning knows, meal planning is much more complicated than it sounds. Avoiding repetition is always a challenge, as is making sure meals strike that balance between nutrition and the sort of indulgence one craves when taking a weekend away. There is always a host of dietary restrictions to meet with any group. The cardinal rule for ours was no grapefruit!

Closing Thoughts

As I look back on my time in Phoenix, I think the thing that stays with me is the optimism. It is hard to reconcile the fact that the lives of the people I have come to know through the IWMF (and respect and care about) are deeply affected by a cancer that is rare and difficult to treat. The people I met in Phoenix came from all over the country, from all over the world, and from a variety of backgrounds, but with one thing common among them, and that is their determination to live their lives to the fullest possible and to join together to make Waldenstrom's a disease of the past. The people I met are truly people of courage.

That's why, of all the kind things I heard after the Ed Forum, this is the one that touched me the most - in half a line from an email that wasn't even supposed to be about the event, not really. Half of a line that I doubt the writer knew would make the recipient tear up a bit midway through her Monday. The half line read: "... for the first time, I heard the word 'cure.' Anything is possible."

Thanks to all of you for giving me the opportunity to contribute in some way, however small, to help expand that possibility.

* * * * *

For links to videos and slides of the formal presentations (and more), we encourage you to visit iwmf.com or visit [facebook.com/waldenstroms.support](https://www.facebook.com/waldenstroms.support) to read "Secret Wallie Musings" for a patient perspective.

BEN RUDE HERITAGE SOCIETY HONOR ROLL



Ben Rude Heritage Society 2017: at the Ed Forum, Laurie Rude-Betts welcomed and thanked new members of the Society for their generosity to the IWMF. Back Row (from left to right): Charles Koch, Joel Rosenblit, Roger Robinette. Front Row (from left to right): Peter Carr, Laurie Rude-Betts, Beverly Bloss, Barbara Robinette.

The Ben Rude Heritage Society recognizes those who have made a planned or deferred gift to the IWMF, such as a bequest, a gift annuity, a trust arrangement, an insurance policy, or a similar planned gift. Legacy gifts represent an important facet of IWMF's financial future. Since the establishment of the Ben Rude Heritage Society in 2008, the contributions of these generous donors have allowed the organization to expand our programs and research commitments exponentially over the years. There is no minimum requirement to join the Society. We invite anyone interested in helping protect the future of WM research and patient services to consider joining the Ben Rude Heritage Society.

For more information on joining, please contact either Dave Benson at dbenson@iwmf.com or 952-837-9980 or Brian Miller at bmiller@iwmf.com

This year, the Society gained nine new memberships and a total \$1,880,070 in current or planned gifts, bringing the Society total to \$7,206,661. Many thanks to all our Ben Rude Society members for making IWMF part of your legacy!

*Deceased ❖Founding Member

New in 2017

JEAN-MARC AUDIBERT*
BARBARA BACKER MARTIN*
AND MARGUERITE BAER
C. EDWIN BAKER*
JACK BAKER
DAVE BENSON
BEVERLY BLOSS
VIVIAN AND ROBERT BOAS ❖
ELSA AND GARY BRADLEY
LESLEY MOORE BRADSTREET
ARLOU BRAHM*
WILLIAM O. BRESNICK AND
ELLEN KANER BRESNICK ❖
RUTH L. BROWN*
L. DON AND MARY BROWN
PETER CARR
GERALD PRESTON CLANCEY*
CHRISTINA CONLEY*
IVY COOPER* ❖
ROBERT* AND ANNE
COULBOURN*
NORM CRANDALL
TONY DYE*
JEAN ELLIS
CINDY L. FURST
JEB GELBER
LESLIE C. GUTHRIE, JR.*
CARL HARRINGTON

JAN HERGESHEIMER
SUZANNE L. HERMS
ARLENE HINCHCLIFFE
WANDA L HUSKINS AND JEFFREY A. PRUPIS
STANLEY KAUFMAN
SHAN ELIZABETH KEARY*
NANCY KERR*
THOMAS KEYS*
EVELYN KLEIN*
GEORGE KNIPELBERG*❖
CHARLES KOCH
DR. ROBERT A. AND CHARLENE M. KYLE
ROY LANGHANS
JANET LEVY
MICHAEL E. LUTTRELL
LENNY MARTIN
JUDITH A. MAY
KATHARINE E. MCCLEARY AND K. EDWARD JACOBI*
KATHLEEN MINER
ANNE AND PETER MITRO
ELEANOR MOORE*
RIC MOORE
MAYNARD MORRIS
SAM AND GAIL MURDOUGH
BRANDT NORQUIST*
JIM AND BETTE ORTOLEVA

ALAN PRESTELL*
MARGUERITE C. REGAN, PHD*
PAUL AND JANICE RIPPAS
ROGER AND BARBARA ROBINETTE
MARGARET ROCKELMAN*
JOEL ROSENBLIT
LAURIE RUDE-BETTS ❖
CYNTHIA RUHL
MARLYN FRIEDLANDER AND GILBERT SCHERER
ELMO R.* AND DOLORES SCHMID*
ALLAN SHAW*
DR. GUY SHERWOOD
ELLEN SMITH
RAY SOBOROWICZ*
JAN SOLOMON CRAMER* IN MEMORY OF MATHILDE JOHANNA VAN GOGH*
KEN AND LINDA SOLOW
CORDELIA AND PETER STEARNS
JUDITH LEE STERLING AND LESLIE CHARLES WILSON
JOHN AND DIANE TIPLADY
RUBEN TROSS*❖
PENNI WISNER
JAMES P YEAGER*
GREGORY FITZWATER AND MARILYN ZOLLNER-FITZWATER
RALPH ZUCKERMAN*

WHAT LEGACY WILL YOU LEAVE?

We all desire significance – to lead happy and fulfilled lives surrounded by family and friends. For many of us, there is a compelling need to make a difference – to leave a lasting impact on the people most dear to us and the world in which we live. The search for significance and a desire to plan for the future lead many to ponder their legacy. What kind of legacy will you leave?

A bequest is perhaps the easiest and most tangible way to have a lasting impact on the people and organizations that mean the most to you. A bequest may also be an effective way to make a gift to charity and lessen the burden of taxes on your family and estate. With the help of an advisor, you can include language in your will or trust specifying a gift to be made to family, friends, or charity as part of your estate plan.

A charitable bequest is a bequest written in a will or trust that directs a gift to be made to a qualified exempt charity when you pass away. One benefit of a charitable bequest is that it enables you to further the good work of an organization you support long after you are gone. A bequest may be made in several ways:

- Gift of a percentage of your estate
- Gift of a specific asset
- Gift of the residue of your estate

Better yet, a charitable bequest can help you save estate taxes by providing your estate with a charitable deduction for the value of the gift. With careful planning, your family can also avoid paying income taxes on the assets they receive from your estate.

Certain types of property pass outside of a will or trust. These

assets require that you name a beneficiary by completing a beneficiary designation form. To make a bequest of these assets, you should contact the company or entity from which you purchased the asset. Below are a couple of examples:

Bequest of an IRA – A retirement asset like an IRA account makes an excellent bequest to charity. If the IRA were given to your family, much of its value would be depleted through estate and income taxes. By designating charity as the beneficiary of part or all of your IRA, the full value of the gift is transferred tax free at your death, and your estate receives a charitable deduction. If you wish to leave your IRA to your spouse at your death, you may also designate charity as the secondary beneficiary of your account. Contact your IRA or retirement account custodian to obtain a beneficiary designation form and make a bequest of your IRA to charity.

Bequest of an Insurance Policy – An insurance policy also makes a nice bequest to charity. As an asset of your estate, an insurance policy is taxable at your death. However, if the policy is gifted to charity, your estate avoids paying tax on the value of the policy and receives a charitable deduction for the gift. You may generally name anyone as beneficiary of your insurance policy and change your designation at any time. Contact your insurance company to obtain a beneficiary designation form and make a bequest of your policy to charity.

Start creating your legacy today. To learn more, contact Dave Benson, IWMF Senior Development Officer, at dbenson@iwmf.com or visit iwmflegacy.com.

This information is not intended as tax, legal or financial advice. Gift results may vary. Consult your personal financial advisor for information specific to your situation.

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MAJOR GIFTS TO THE IWMF

RESEARCH PARTNERS

For a commitment of \$50,000 per year for a minimum of two years, or a lump sum of \$100,000 or more, you can become a Research Partner supporting a specific IWMF research project approved by our Scientific Advisory and Research Committees. Research Partners will have an opportunity to be kept informed of the progress of the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. We generally have 4 to 6 research projects underway with new projects under consideration throughout the year.

David & Janet Bingham Research Partners Fund of the IWMF

Robert Douglas Hawkins Research Partners Fund of the IWMF

Michael & Rosalie Larsen Research Partners Fund of the IWMF

Carolyn K. Morris Research Partners Fund of the IWMF

K. Edward Jacobi Research Partner Fund of the IWMF

Marcia Wierda Memorial Research Partner Fund of the IWMF

NAMED GIFT FUNDS – For a commitment of \$10,000 per year for five years, or a lump sum of \$50,000 or more, you can establish a named fund at the IWMF in your own name or in the name of someone you wish to honor. This fund may support Member Services or Research or a combination of the two.

Baker Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Samuel Schneider Research Fund of the IWMF

Lynn Martin & Carrie Wells Research Fund of the IWMF

Gail Murdough Member Services/Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

If you have discretionary giving power and would like to help move our research program forward in a special way we invite you to join those listed above. For more information about

Major Gifts, cont. on page 22

Research Partners and Named Gift Fund opportunities and possible gifting options that might make that possible, please

contact Dave Benson, IWMF Senior Development Officer at (952) 837-9980 or dave@dbenson.com

YOUR CONTRIBUTIONS ARE THE FUEL THAT KEEPS YOUR IWMF RUNNING

As you know, the IWMF is a charitable 501 (c)(3) organization, and the majority of our donations come from members and supporters just like you. People give to organizations for all sorts of reasons. Why should you choose to support the IWMF?

Is your chapter Support Group Leader so awesome that he or she brings in great speakers, gives out a home phone number to support you through some tough times, or makes you feel heard and supported? Did the anniversary pass of your loved one who died with Waldenstrom's macroglobulinemia and you wanted to honor his or her memory with a special gift or multi-year pledge to your loved one's favorite charity, the IWMF? Was the office staff instrumental in getting you the answers to your questions when you first called after your frightening diagnosis? Or, if they did not have the answer, did they direct you to the answers by recommending IWMF Connect (formerly IWMF-Talk)? And to our publications? And to our website, iwmf.com?

The fact of the matter is that donating to honor and to memorialize friends and family is the best way to empower our organization to keep these valuable services available to all. While we strive to be a caring and thoughtful group of fellow patients and staff, we also strive to raise funds to

maintain and add to all the services that you want and need: the two are not mutually exclusive.

There are many convenient ways to give back. We have donors who pledge small amounts on a monthly basis. We have memorial gifts sent to our office because an obituary suggests that donations should be made to the IWMF in memory of a friend or family member. And we receive significant gifts from donors who are so moved by the love and support that they, their parent, or their sibling got from the IWMF that they want to do all they can to continue that support for those who will also benefit.

Whatever your financial situation, no matter how large or small your gift amount is, this is the deal: they all add up, and they all help! Contributions fund member services and research. They are the fuel that keeps your IWMF running, from advancing new and promising research proposals to, for example, printing this *Torch* – pretty much everything.

So, thank you for writing checks, for making donations on our website iwmf.com, and for pledging generously. You are the lifeblood of the IWMF, and we would not be able to do what we do without your generous support. You know, a gift to the IWMF is one gift you give right back to yourself.

SUPPORT GROUP NEWS – UNITED STATES

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

Southern CA

Los Angeles/Orange County

The Southern California chapter held its bi-annual meeting on April 8 in Anaheim. About 30 veteran and new members gathered for a light lunch and presentation by Dr. Tanya Siddiqi from City of Hope in Duarte, CA. She spoke about novel therapies for WM and took questions from the group. Dr. Siddiqi is currently collaborating with Dana-Farber Cancer Institute to open clinical trials for WM at City of Hope.

San Diego Area

In April, **Kathy Battle**, Support Group Leader, gathered 17 attendees for the area's inaugural meeting. Kathy hosted an outdoor brunch on the patio of her Oceanside home on a beautiful morning. The 12 WMers in the group shared their stories. Then the members discussed meeting at least quarterly, with some of the meetings having a medical provider speaker and others reserved for social time and group sharing. Ideas for times and places were shared and will be researched with a plan to meet again later in the summer.

COLORADO and WYOMING

On a beautiful 75-degree April Saturday in sunny Colorado, 525 blood cancer patients, caregivers, nurses, doctors, and interested others gathered for the seventh annual Rocky Mountain Blood Cancer Conference, which took place in Aurora, CO, near the Colorado University Anschutz Cancer Center. Every year the event is bigger and more successful.

Support Group News, cont. on page 23



Bill Bass (left) and Elsa Bradley (right), Colorado Support Group Co-Leaders, with Julie Jakicic (center), former IWMF staffer in Sarasota now on the staff of the Denver Leukemia & Lymphoma Society. Julie has been invaluable in providing us with "what will help us the most" here in Colorado.

The IWMF hosted a table to display its materials in the exhibit hall. Local WM support group leaders successfully campaigned to get a special WM breakout session. Eighteen people attended to listen to Dr. Jeffrey Matous, Director of the Colorado Blood Cancer Institute in Denver. Dr. Matous covered the basics of WM, how it is diagnosed, typical symptoms, how and when to treat, the importance of the MYD88 and CXCR4 gene mutations, new drugs coming up, and clinical trials available here in Colorado. He also covered the results and conclusions of the Ninth International Workshop on WM held in Amsterdam, October 2016. Both Dr. Matous and his Nurse Practitioner, Megan Anderson, attended the Workshop. Three newly diagnosed patients attended Saturday: one couple from northern Colorado, one couple from southern Colorado, and another couple from Albuquerque! It was extremely informative for them, and they were delighted to meet and share with WM veterans. At lunch, the conference attendees were seated at tables by disease: the two tables of WMers and friends could then talk informally, continuing various discussions and sharing information gathered from personal experience while having a nice meal. In the afternoon two more breakout sessions were available on different topics, and each attendee could pick the two that he or she needed most. It was a terrific day, well organized, great for WMers and all who attended. A special delight occurred when Dr. Matous was awarded the prestigious Dr. John J. Kenny Award by the national Leukemia & Lymphoma Society (LLS) for his extraordinary work in helping cancer doctors, patients, other support groups, and his community! Dr. Matous was very surprised and very pleased! What a beautiful and great day for WMers in Colorado!

ILLINOIS

Chicago Area/SE Wisconsin

The group is having a great year with a visit in June from Dr. Steven Treon of Dana-Farber Cancer Institute and another in the fall from Dr. Sherine Elsawa, assistant professor of immunology at Northern Illinois University. The annual summer picnic falls between these events on Saturday, August 5, at **Sara Thrane's** home in Elgin, Illinois (on the west side



Dr. Jeffrey Matous, rear, speaking to our group about WM at the LLS-sponsored seventh annual Rocky Mountain Blood Cancer Conference. On this occasion, Dr. Matous received the Dr. John J. Kenny Award from the national Leukemia & Lymphoma Society for his extraordinary service in helping cancer doctors, patients, other support groups, and his community.

of Chicago). The picnic is focused on fellowship and good food. Details of the June meeting will be in the fall *Torch*. Dr. Elsawa will present an update on her Waldenstrom's research. An October date for this event will be announced.

INDIANA

Fourteen patients and caregivers gathered on the first weekend in May at the Leukemia & Lymphoma Society (LLS) office in Indianapolis. One new patient attended and plans to attend the IWMF Ed Forum in Phoenix as well. The more experienced group members shared everything they knew with the new member of the special WM club and her husband. The information "download" allowed everyone to check in with each other. A round-table discussion focused on living with a chronic illness, including how the patient feels about having a chronic illness and how to cope. Much sharing came out of this discussion, and the conversation was lively. Participants enjoyed bagels, coffee, and miniature Snickers during the meeting. An early August date may be the best time for the next meeting. Watch the IWMF website for the date announcement.

MICHIGAN

Fourteen people gathered in April at the Providence Hospital's Heart Institute in Novi. They shared their experiences living with or supporting someone with Waldenstrom's. The group included four new attendees while the rest were returnees. Offering a second location for meetings in Grand Rapids was discussed. Cathy Alcala, new to the group, volunteered to help organize and to get this accomplished. Members expressed a desire to have a guest speaker for the next meeting. Meetings in both locations are in the planning stages for next September before the snowbirds fly south for the winter. Please check the iwmf.com EVENTS listings for days, times, and locations.

NEW YORK

New York City

On April 23, the NY-Metro support group was treated to a two-and-one-half-hour presentation by Dr. Steven

Support Group News, cont. on page 24

Treon that achieved so many things – it gave the group an understandable primer on the newly (if still only partially) understood biology of WM, then moved on to discuss, at a high level, the wide range of promising genomic work ongoing in Dr. Treon's lab at Dana-Farber Cancer Institute (DFCI). It was a thrilling morning co-sponsored by the Bing Center for Waldenstrom's Macroglobulinemia at DFCI and the local IWMF group. About 85 participants – patients and caregivers – were present to hear what Dr. Treon had to tell us. Luckily for the group, Dr. Lia Palomba of Memorial Sloan-Kettering (MSK) provided the space needed to hold so many participants. MSK kindly provided the caffeine and refreshments that kept individuals stoked for the lecture and Q&A. Dr. Treon is a fabulous teacher and an exceptionally generous human being. He has dedicated his career to the fight to conquer WM. It was a privilege for all to have a morning with him.



On the occasion of Dr. Treon's presentation to the New York-Metro Support Group: from l. to r., Chris Patterson of DFCI, NY-Metro Support Group Leader Mitch Orfuss, Dr. Lia Palomba, and Dr. Steven Treon.

Eastern NY and Western New England

After a winter hiatus, on May 7 over a dozen group members enjoyed their annual spring luncheon at the Capital Buffet in Colonie, NY. They discussed fundraising and the planned June program, which will feature reports from the IWMF Educational Forum in Phoenix. Three members plan to attend the forum and will discuss their impressions.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

On a beautiful Sunday afternoon in early April, the group met at a comfortable library facility in North Royalton, OH, to catch up after the winter hiatus and to share thoughts of hope. The focus of the discussion was "staying hopeful, realistically" to maximize our quality of life within our personal limitations. One member shared her experience of staying hopeful by continuing to make plans with guarded optimism. This idea resonated with other group members who felt that it is important to live life as normally as possible, adjusting for WM when necessary. Long-term members of 10-20 years or more reflected that living hopefully was more of a challenge in earlier years when life expectancy after diagnosis was in the range of 5 years. All agreed that the new treatments and understanding of WM-related genetics is creating a surge in life expectancy and feelings of hope

– personally illustrated by a member who shared success with a new clinical trial at Dana-Farber Cancer Institute. A variety of snacks, fruit, and desserts fueled animated chatting before and after the group sharing.

TEXAS

Houston

In March the Houston group gathered for good talk, cookies, and wine provided by members. The hope had been to Skype with Jorge Castillo, MD, of Dana-Farber Cancer Institute, but try as he might, when the time came, he could not get free. The group was at first disappointed but quickly turned to the DVD of Dr. Castillo's presentation to the 2016 IWMF Educational Forum in Providence, RI. In this presentation he covered many of the questions that had come up during the sharing part of the meeting. In addition, Dr. Castillo has offered to reschedule. Plans are afoot for a meeting in August and, in the fall Dr. Steven Treon is expected to visit the group.

NORTHERN VIRGINIA/WASHINGTON DC/ WESTERN MARYLAND

Speaking to a sold-out crowd of over 100, double the usual numbers attending the support group meetings, Dr. Steven Treon of the Bing Center for Waldenstrom's Macroglobulinemia at Dana-Farber Cancer Institute reported on the Center's latest advances in clinical and laboratory research. Dr. Treon traveled with Christopher Patterson, Administrative Director of the Bing Center, which cosponsored the meeting with the local IWMF support group. Motivated patients and caregivers came from Virginia, Washington DC, Maryland, Delaware, North Carolina, and even California to learn the latest news. Dr. Treon reviewed whole genome sequencing, including the Bing Center's pivotal discovery of the genetic mutation on MYD88, expressed in 95% of WM patients. He also discussed novel therapeutics for Waldenstrom's patients and an increase in survival prospects realized through current clinical trials. His presentation was followed by a thorough question-and-answer period. Even after the close of the program, Dr. Treon continued to answer individual patient questions. Christopher Patterson provided reprints of several of the most recent articles authored by Dr. Treon and his Bing Center laboratory team. With a lively, standing ovation, the audience expressed



The turn-out for Dr. Treon's visit on a cold day in mid-April was large and enthusiastic. Dr. Treon stands fourth from the left in the second row; Support Group Leader Lu Kleppinger is sixth from the left in the front row.

its deep gratitude for this tremendous opportunity to hear from Dr. Treon in person. For **Lu Kleppinger**, support group leader, the most inspiring and unforgettable thing she heard

Dr. Treon say was, “In our search for a cure, we won’t settle for anything less!”

IN THE TORCHLIGHT WHEELING IT WITH WALDENSTRÖM!

BY WANDA HUSKINS

“All the golden land’s ahead of you and all kinds of unforeseen events wait lurking to surprise you and make you glad you’re alive to see.”

Jack Kerouac

Kerouac’s call to the road was heard by Wanda Huskins and husband Jeff Prupis who, nine months ago, set forth together to experience events then unforeseen in our golden land and to be made “glad they’re alive to see.” Wanda here sends a letter to those of us who are, perhaps, less adventuresome but admire their determination that “having WM brought us to live more purposely.”

On September 1, 2016, we departed from home ownership in New York and embarked on a life as full-timing RVers. Wheeling it with Waldenström! We left with our few possessions and our two precious cats, lingering a moment in quiet reflection on the well-worn path that brought us to this new, unknown one.

Whether you call it a RV, a class A Motorhome, Coach, or Rig, we call it Home. Home is where we park it. And Home has been parked in so many gorgeous settings that I’ve lost count. As a former homebody, surprisingly, I’m now excited to arrive at each new destination and to become totally immersed in all we see and find. But equally as happy to travel on to adventures that await us.

Our travels have brought us down the eastern seaboard from New York to Florida, then across Texas, New Mexico, Arizona, into California and the Northwest where national and state parks became our temporary back yards. We become captivated by history, geography, geology, and plant and animal diversity every time we visit “America’s Best Idea.” And when “dry camping” (that is, without hookups) we can experience nature at her finest in the more remote and secluded areas.

We’ve been able to catch up with family and friends, even becoming acquainted with Wallies along the way. We made sure to stop by the IWMF office in Sarasota, Florida, to say “Hello” and offer thanks for the hard work that goes on behind the scene. There are no typical days for us. New wonders continue to surface for us to explore. We may plan a scenic drive, or leisurely walk on a nature trail, or find a gentle bike path, or launch our tandem kayak on a picturesque lake. We’ve crossed paths with bald eagles, elk, armadillos, javelinas, elephant seals, wolves, coyotes, and even a young mountain lion.



Wanda and Jeff at Home on the Road

Our two cats have managed to adjust equally well to the travel lifestyle. Dolce, the 18 year old, seems to be thriving on the experience. He eagerly awaits his leash for me to walk him outdoors, while younger Bene is finally coming around to the RV bouncing on travel days. Like us, this has become their new normal, too.

At some point the feeling of a vacation became “this is our life.” We have our daily routines and chores like anyone else, and some include less than glamorous tasks, such as emptying the holding tanks. Beyond the predictable issues, there have been some unpredictable ones. We’ve been stuck in a tropical storm in South Carolina, been evacuated from a hurricane in Florida, and caught by a sandstorm in Death Valley.

As Free Wheelers we can go where we want, when we want, but WM as a passenger adds a dimension of risk-taking that my roadie peers don’t contend with. People I know living with cancer, including many I’ve heard from with WM, have voiced concerns of needing the safety net of their health team nearby. Having health scares on the road is a concern I share as well. I’m mindful that health uncertainties persist, but I’ve tried not to allow WM to define how I live my life.

We are frequently asked how long we plan to do this. Our usual response is “Till we run out of road, no longer want to, or simply because we can’t. Having WM brought us to live more purposely, and there are no plans to change that.”

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

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

UNITED KINGDOM

Spring was challenging, trying to improve treatment in the face of austerity. The stem cell transplant restoration campaign had been successful, but, sadly, at the time of writing, the expected approval for ibrutinib for relapsed WM has not materialized after 6 months, although the initial National Institute for Health and Care Excellence (NICE) provisional rejection was reversed. WMUK and Janssen UK, supported by other UK blood cancer charities, put in an immense amount of work with regulator NICE, but talks to allow ibrutinib to enter the Cancer Drugs Fund have been glacially slow, particularly on the data collection specification needed, including the help of our Rory Morrison Clinical Registry.

This delay slowed down the national roll out of the Registry, but 12 UK hospital data collection centres have now been identified. It must be stressed that this is a clinically validated Registry of treatment data by doctors, so fundamentally different to the Australian WHIMSICAL Database of patient-entered data. However, subject to funding, our Registry plans to have remotely entered patient “quality of life” data, possibly via a mobile app.

In other areas things have been more positive; with imminent trials – notably for BGB-3111, a “second generation” BTK inhibitor, after an initial delay. The WMUK doctor group has established a trials hub to spread information, as it was clear that those treated in smaller centres had less chance of access to trials and that the UK generally lagged behind continental Europe in the number of trials. The group is also establishing self-nominated centres of WM interest – usually in larger hospitals treating substantial numbers of WM patients where specialists are happy to accept referrals.

The popular guide to WM produced by Dr. Shirley D’Sa at University College London Hospitals (UCLH) has been updated and was available from May on the WMUK and IWmf websites. There are plans in hand for other mini guides in areas such as amyloid and for short video talks by experts and patients on a range of topics for the website.

The WMUK Biobank moved ahead, co-financed by the IWmf and WMUK, and WMUK was able to make a further grant in March towards a new -80C freezer at UCLH to store more tissue samples. WMUK-funded research at the doctoral level on DNA cell lines continues successfully at Leeds via Dr Roger Owen, and we were also able to make a substantial grant to buy DNA test kits at UCLH and Bournemouth, part of increasing the pressure to have all UK patients tested for the well-known mutations.

Planning for the July 16 Patient/Doctor Summit Meeting at St. Catharine’s College, Oxford, is well advanced. This year formal talks are reduced, and a number of innovations include an “early bird” session for the newly diagnosed, a session

for handling the psychology of WM, and a breakout for the younger WM patient. This is increasingly an area of interest in that younger patients sometimes have a different disease progression and may need more support in managing jobs and families. The popular “Ask the Doctor Lite” sessions remain.

Finally, in light of the useful information gathered from last year’s treatment survey (largely to support the ibrutinib application) we envisage launching a rolling online treatment survey in the autumn to tease out aspects of treatment variation and patient experience throughout the UK.

To keep up with news, all please sign on our website www.wmuk.org.uk to receive our e-newsletter and details of our UK online forum.

Roger Brown, WMUK, reporting from deepest Epping Forest.

AUSTRALIA

WMOZZIES PATIENT IS AWARD WINNER

Michael van Ewijk’s testimonial on his WM experience helped win a \$50,000 US competition prize for the ClinTrial Refer App. “I was diagnosed with Waldenström’s macroglobulinemia, a rare lymphoma, in 2005. After years of treatments that didn’t work, I was able to get onto a clinical trial for a new drug. It has turned my life around. My haematologist in Wollongong (over 50 miles from Sydney) found the trial in Sydney by looking up the ClinTrial Refer App. This app has saved my life and gave me the best years of my life I have had for many years.”

The US “Clinical Trials Innovation” worldwide competition was initiated to produce breakthroughs in increasing patient accrual to clinical trials. ClinTrial Refer is a transformative app connecting patients, doctors, and clinical trials. It has demonstrated a 9-fold increase in cross-referrals between hospitals to clinical trials and a 60% increase in patient enrolments. The app encourages collaboration between trial sites.

Co-inventor of the app, **Associate Professor Judith Trotman** (Principal Investigator of WHIMSICAL Database) said, “ClinTrial Refer is a tool in the collaboration amongst clinician researchers in breaking down traditional hospital silos. With ClinTrial Refer we have shown that doctors will refer, and patients will travel, to access lifesaving therapies.”

LEUKAEMIA FOUNDATION LYMPHOMA TELEPHONE FORUM

The forum held on April 5 was so well attended that it was organised as totally questions and answers. Questions were submitted in advance to ensure best and widest coverage in the hour and a half forum.

International Scene, cont. on page 27

The draw card for the Forum was **Associate Professor Constantine Tam**. WMozzies had the opportunity for questions based on his wide WM expertise, experience, and contribution, which include

- Joint author of Australian Clinical Practice Guideline Waldenström's Macroglobulinemia.
Principal Investigator iNNOVATE randomised, double blind Phase 3 study for Waldenström's macroglobulinemia patients involving ibrutinib or placebo in combination with rituximab.
- Principal Investigator in clinical study: Comparing BGB-3111 and Ibrutinib in Subjects with Waldenström's Macroglobulinemia and MYD88 Mutation.
- Investigator WHIMSICAL Database.
- IWMF Directory of WM Physicians – Australia.

His response to questions from WMozzies included wide-ranging comments such as:

- Ways WM patients can help achieve better patient outcomes through greater collaboration with specialist.
- How can WM patients collaborate with haematologists and the Leukaemia Foundation in advocating to bodies such as the Pharmaceutical Benefits Advisory Committee for better drug access in Australia for WM patients?
- Comments about the importance of the WHIMSICAL Database for WM patients and WM research.
- Positive feedback about the WHIMSICAL Database he had received at the IWMF9 workshop in Amsterdam, October 2016.

FUNDRAISING FOR BLOOD CANCER RESEARCH

WMozzies member **Mary Nassibian** is again one of the fundraisers for blood cancer research for the Concord Cancer Centre at Concord Repatriation General Hospital on 15 September.

The 2017 target is \$160,000 to fund two additional clinical research nurses so that more patients with life threatening blood cancers can participate in research and access innovative treatments that would normally cost millions.

CELEBRATION OF LIFE

Many WMozzies were guests of the Concord Cancer Centre at the Blood Cancer Patients Celebration of Life Cocktail Party. The Haematology forecourt was brilliantly decorated with flowers and balloons. Soft lights and live orchestral music with favourable autumn weather made it a splendid occasion.

Feature speeches at the function included:

- Associate Professor Ilona Cunningham – Concord Cancer Centre's work.
- Associate Professor Judith Trotman – Clinical Trials.
- WMozzies **Michael van Ewijk** – speech and video

supporting ClinTrial Refer App.

- Dr Ibrahim Tohidi-Esfahani - Principal Investigator WHIMSICAL Database.
- Son of late WMozzies member **Raymond von Konigsmark**, who had died a fortnight before, in appreciation of his 18-month participation in BGB-3111 Clinical Trial at Concord. Raymond's results were amazing. His participation in the trial stopped on February 2 when he was diagnosed with an advanced cancer considered unrelated to his WM. Raymond had WM for 19 years, and during this time he always took control of his life and never allowed WM to control it. He enjoyed life to the full and always had a sense of humour to travel through adversities.
- WMozzies **Andrew Warden** – use of ClinTrial Refer App in finding Clinical Trial at Concord Cancer Centre.

Andrew Warden, WMOZZIES, reporting.

SCANDINAVIA

From Scandinavia we report a few “mini meetings.” There are few people with WM and we are spread over large areas. It can be an adventure (and costly as well) to get to and from small places. This means that a digital forum or local meeting in the larger cities fits best.

WM Scandinavian has, within this first year, grown to 94 members. We can be proud of such a good beginning! The biggest news to report is that Eva Hoff Wanderås has translated the IWMF Fact Sheets into Norwegian, one of the Scandinavian languages.

Susanne Öhrn, WM Scandinavia reporting.

INDIA

FIRST TIME NEWS FROM INDIA

Two regional representatives in Calcutta (Kolkata), namely Anil Somani and “yours truly”, met six times in the last seven months to exchange notes and create a patient database. We also encouraged newly detected patients and caregivers to join IWMF, to attend annual meetings, and to learn about Waldenström's macroglobulinemia from the resources available on iwmf.com

Last November we were able to provide support for a Chinese national who flew in from Beijing to have a second opinion from a specialist in Calcutta.

We hope to provide greater outreach in the years to come.

Rajat Saha, reporting from Kolkata, India.

FRANCE

2017 is a year of elections in France – and not only at the national level. Waldenström France recently elected a new team and a new president. President François Soulié comes with an innovative roadmap and pragmatic plans for patient support. Our annual patient-physician meeting will take place on September 23, in Limoges, West Central France.

François Soulié, President, and Valérie Debaix reporting.

YOUR HELP NEEDED

IWMF ANNOUNCES NEW WM-SPECIFIC PATIENT DATABASE

BY PETER DeNARDIS, IWMF TRUSTEE

In May the IWMF formally announced the deployment of a newly developed patient- and medical researcher-led global database (the first of its kind) for Waldenstrom's macroglobulinemia called WHIMSICAL (Waldenström's Macroglobulinemia Study in CART-WHEEL).

WHIMSICAL was originally launched in 2016 by an Australian research team led by Principal Investigators Dr. Ibrahim Tohidi-Esfahani and Associate Professor Judith Trotman (Concord Cancer Center, Australia). Participants entered their data into Australia's CART-WHEEL (Center for Analysis of Rare Tumors), which is an ethically approved patient database utilizing the BioGrid Australia secure database platform for rare cancers. BioGrid Australia is a well-established web-based, real-time, data-sharing platform for collaborative, translational medical research linking de-identified, ethically approved data across institutions and jurisdictions.

Following Australian promotion in 2016, the feasibility of WHIMSICAL was confirmed with 66 patients recruited. In 2017, pathology test result graphing and online consent were implemented, leading to the recently announced collaboration with the IWMF and global rollout.

The IWMF is encouraging WM patients around the world to participate in the database. (Note: for now, the database is only available in English.) A goal of recruiting at least 200 patients by July has been set.

The more patients participate, the better the chances for the research team to submit an abstract to ASH 2017 and have it approved for presentation, demonstrating the global feasibility of WHIMSICAL.

With the participation of WMers around the world, a significant increase in WHIMSICAL data is anticipated in coming years. The breadth of information gathered will expand knowledge of the range of WM treatments and outcomes. This will complement the depth of data derived from clinical trials and site-based registries. Demonstration of any treatment disparities, coupled with information regarding treatment efficacy, may facilitate novel therapies.

The WHIMSICAL database was presented at:

- 9th International Doctor-Patient Forum on WM (IWWM9) in Amsterdam, 9 October 2016. IWMF President Carl Harrington hosted a special briefing at IWWM9 on the WHIMSICAL database for international WM researchers and clinicians from the US, UK, Netherlands, Germany and Greece, generating strong interest and support.
- Meeting at the Melbourne Convention and

Exhibition Centre, 15 November 2016. Dr. Steven Treon of the Dana-Farber Cancer Institute, who spoke at the meeting and conferred with WHIMSICAL Principal Investigators, declared that he "is excited to support WHIMSICAL."

Below is the text of the IWMF's announcement, along with instructions for doing your part in advancing the knowledge of and treatment methods for Waldenstrom's macroglobulinemia.

WHY JOIN WHIMSICAL?

If you want to "pay it forward" and help current and future WM patients around the world, then join WHIMSICAL!

WHAT IS WHIMSICAL?

WHIMSICAL is the first *patient- and medical researcher-led global patient database for Waldenstrom's macroglobulinemia*. Developed first for use in Australia, it is now being rolled out globally and uses the same analytical framework used for many other rare diseases.

WHAT WILL WHIMSICAL DO?

WHIMSICAL will capture patient data for WM patients globally.

DOESN'T SOMETHING LIKE THIS ALREADY EXIST?

The short answer is no. Efforts to create a global database have been conducted by the IWMF in the past, but not as extensively or as scientifically valid as WHIMSICAL promises to be. Also, while major medical centers have records of their patients' medical histories, they do not necessarily share those data with each other. WHIMSICAL is the only database thus far that collects patient data from around the world in one centralized location.

WHAT IS THE VALUE OF A GLOBAL PATIENT DATABASE?

Have you heard the term big data? Big data analytics is the process of examining large and varied data sets – *i.e.*, big data – to uncover hidden patterns, unknown correlations, market trends, customer preferences, and other useful information that can help organizations make more-informed decisions. That's where WHIMSICAL is heading. First, we need to get a sufficient number of WM patients to enter their data. Then we need to compare it to information at medical institutions to make sure they correlate. Then we can use those data to inform our understanding and to help frame further research needs leading to insights into WM.

Your Help Needed, cont. on page 29

WHAT DO I HAVE TO DO?

You can sign up to participate in WHIMSICAL at www.cart-wheel.org

(For more information about WHIMSICAL and how to sign up to participate, go to:

<http://www.wmozzies.com.au/index.php/whimsical>)

Once you are registered, start filling in your personal data for WM. You will need information such as:

- Your past blood test results, e.g., IgM values, hemoglobin, serum paraprotein, M-protein, neutrophils, platelets, beta-2 microglobulin, among others.
- Your WM symptoms and past treatments.
- Your personal and family medical history.

Don't worry if you do not have all the information handy. Just fill in the data that you do have for each time you had blood tests or treatments. It is suggested that you start with the data from your date of diagnosis, at the completion of each treatment course you've had (that is, after all cycles of a course are completed), and your most current data, and then work your way back, adding additional data as you have time to do so.

HOW LONG IS THIS GOING TO TAKE?

That depends upon you and how long you've had WM, what treatments you've received, the tests performed, etc. You should probably expect to spend between thirty minutes and three hours. Relax, though, as you don't have to do it all in one sitting! You can start and stop and go back again to where you left off.

WHAT IF I'VE PREVIOUSLY PARTICIPATED IN THE IWMF PATIENT DATABASE? WILL THAT STILL BE AVAILABLE?

Any data you entered into the IWMF Patient Database will have to be re-entered into the WHIMSICAL database. The advantage of the new database is that it is being driven by both patients and researchers and will be considered more scientifically valid from a research perspective.

The IWMF is encouraging its members to participate in the WHIMSICAL study database. During the transition from the IWMF Patient Database to WHIMSICAL, the original PDB will remain active and available; however, no further maintenance or development will occur, and new members will not be enrolled.

Please join us in moving forward towards "big data" collection for Waldenstrom's macroglobulinemia on behalf of patients, caregivers, scientists, researchers, and clinicians around the world!

WHY SHOULD I DO THIS AGAIN?

If you appreciate and have benefitted from the greater knowledge that we have now about WM and want to have better treatments with fewer side effects for yourself and future WMers, then you need to do this. It will help us get closer to a cure and benefit WMers and WM researchers across the globe. Consider it your personal scientific contribution to conquering WM. As a bonus, you'll be able to track your own personal pathology test results in tabular and chart/graph fashion.

If you have any queries about WHIMSICAL, please contact whimsical@iwmf.com

"A Big Family Reunion" 2017 Additional Photos



**BETWEEN FEBRUARY 1 AND MAY 31, 2017, THE FOLLOWING CONTRIBUTIONS TO THE
INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

William A.S. Akana
Margaret Akana

Spiro Anagnos
Sally and Chuck Simpson

Gary Baur
Yvonne Baur
Allison Booth
Roger Brecht
Julie Caracappa
Jim and Jill Hartz
Jean Kaplan
Joe and Bev Kress
Emily Matson
Heather McNutt
Terri Schulte
TCHS Class of 1964
Peter Teets

Robin Benjamin
Meryl Nierman

Morton Berger
Bob and Eileen Whitman

Joan Berglund
Joel Rosenblit

Lou Birenbaum
Fay and Maurice Langer

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Charlene Heuer
Michael and Jane Marovich
Annette and Bill Murray
William and Karen Secor

**Frank, Madeline and
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Marie Martorana

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Kristol Kempin
Lucille Killiany
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Johnston O-Connor
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Walter Robinson
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Christine Woods

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Keith and Mary Bloomquist
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Gay Lesmister

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Midhu Varghese

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Laurel and Emily Michel

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English Auto Society

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Judy and Jerry Gillett
Sandy and Jason Gross
Daivd and Barbara
Hochman
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Maureen Sullivan

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Nita Pattridge Swisher

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Lucrezia Vassallo

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Harold Wesmiller

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Kathleen Sue Brandt
Karen Mulder
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Ruth Buono
Bella Kaplan
April Miller
Susan Richards

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Sandra Blais

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Martin Brynien

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Don, Marlene, Doug and
Mary Kottler

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Michael and Jan Dulin

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George and Kathy
Coutrakon

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Drew Honaker

Beata Howe
George Hood

Dorrie Iten- Gilden
Elise Gilden

Michael Jacobs
Gail Jacobs

**Judith May & Michael
Luttrell**
Ronald and Sally Munro

Prashant Kapoor, M.D.
Michelle and Scott Blazek

Ellis R Kennedy Sr.
Ellis Kennedy

Dr. Steven Krause
Jerry and Karen Eisman

The Kryl-Cintron Wedding
Alejandro Diaz
Caroline and John Kryl
Stephanie Smith
Ed and Shelia Stranc

**The Kryl-Cintron
Wedding (cont.)**
JoAnn Worthy

Dr. Robert Kyle
Phil Cacioppo

Glen Machesney
Suzanne Machesney

Elena Malunis
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IN APPRECIATION OF RON YEE

During the Welcome Dinner at the 2017 IWMF Educational Forum, a Lifetime Achievement Award was presented to Ron Yee. President Carl Harrington made the following remarks about Ron's life and service.

Ron Yee served on the IWMF Board of Trustees from 2004 - 2015 (acting at times as the "resident Information Technology expert" during meetings).

He served on the Publications Committee, Finance Committee, Research Committee, and Ed Forum Committee, and was active in the New York City and Philadelphia Support Groups - all while holding down a demanding full-time job in the pharmaceutical industry and being a doting husband and father for his family. He was very handy, "rehabbing" his house and his kids' apartments, and he loved to ride his motorcycle with a group of older buddies.

Ron's main organizational volunteer interest was in the IWMF, but he offered countless individuals his personal support and encouragement, and not just people with WM.

I know a lot of you remember Ron's presence at the Ed Forums, with an ever-present smile and boundless energy, assisting folks to their seats and to the microphones when they wanted to ask questions of the speakers. He was also outgoing and engaging and introduced himself to first-time or newly diagnosed patients at every Ed Forum, hearing their stories in such a caring and gentle way. Actually, Ron exhibited his gentle spirit towards everyone he encountered with enthusiasm and optimism and *joie de vivre*. He used to tell folks that attending an Ed Forum "re-charged" his batteries because he was always happy for the opportunity to offer support to others so that they wouldn't feel so alone with this disease.

So it is especially appropriate that we honor him here, at an Ed Forum.

Thank you, Ron for all your years of service. We truly miss you.

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