

INSIDE THIS ISSUE

Dental Considerations
with Waldenstrom
Macroglobulinemia.... 1

President's Corner 3

Celebrating Ola Ferla... 4

Using Advance
Medical Directives..... 6

In The Torchlight 8

Medical News
Roundup 10

From IWMF
Connect..... 13

The Elting Family
Initiative..... 15

IWMF Doc Star:
Zachary Hunter 17

Cooks' Happy Hour ... 18

International Scene.... 20

EHA Meeting in
Madrid..... 22

Support Group
News 23

A Patient Patient 29

DOCTOR ON CALL: LINDA P. NELSON, DMD, MSCD



Dr. Linda P. Nelson

DENTAL CONSIDERATIONS WITH WALDENSTROM MACROGLOBULINEMIA

Following an extremely active career in the field of pediatric dentistry, Dr. Nelson recently retired from the Harvard School of Dental Medicine where she was a member of the faculty from 1996-2016 and held many administrative positions. Linda Nelson is a Trustee of the IWMF.

When is the best time to have major dental problems taken care of when diagnosed with symptomatic Waldenstrom macroglobulinemia (WM)? The best answer is prior to the diagnosis! Most major dental problems that are seen in patients with WM are not a direct manifestation of the disease itself but are problems resulting from untreated dental infections that have been subclinical (smoldering) and now reveal themselves as a result of immunosuppression or low blood counts that accompany high serum IgM levels. The time to have major dental procedures is not when the patient requires rapid control of symptomatic disease. Consultation (always a good idea) with the patient's oncologist, oncology nurse practitioners, dentists, dental specialists, hygienists, and dieticians can often achieve highly effective preventive and therapeutic dental care. A multidisciplinary approach is warranted because of the medical complexity of the patient with symptomatic WM and because a regimen of therapy affects dental treatment planning, prioritization, and timing of dental care.

General Dental Considerations

Dental care is an important consideration for patients with WM for multiple reasons:

1. the initial or presenting symptom of the disease is often unexplained and frequent oral bleeding or bleeding gums with no history of gum (periodontal) problems,
2. the presence of hyperviscosity (excess thickness of the blood due to high serum IgM) may be suggested by frequent, spontaneous gum and nasal bleeding,
3. patients who have excellent oral health before starting chemotherapy or immunotherapy are less likely to have complications and mouth sores (mucositis) from their drug therapy (ibrutinib, for example) than are patients in poor oral health,
4. the best time to have major dental procedures, such as implants, root canals (endodontics), extractions (removal of teeth), or gum surgery is not when patients are fatigued, have muscle aches, low serum IgG levels, low blood cell counts (neutropenia) making them less able to fight infections, or when their platelets are low (thrombocytopenia) and are less able to stop bleeding.

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Dental Considerations, cont. from page 1

Oral or Nasal Bleeding may be a Symptom of WM

Although there may be frequent, uncontrolled, spontaneous bleeding along the body's entire mucosa (lining of the gastrointestinal tract), it is not as immediately obvious to the patient as it is from the nose or gums. In patients with WM the cause is a low red cell count and/or low platelet level resulting from a high serum IgM level. Bleeding gums or nosebleeds can be the initial symptoms that bring patients with WM into their doctor's office for a diagnosis. Of course, other conditions may be the cause of the spontaneous gum and/or nasal bleeds, but it is part of the hypothetical or differential diagnoses that the medical team will consider when ordering medical tests. In WM, when the IgM level is reduced by drug therapies or plasmapheresis to a safer level, the spontaneous bleeding from the gums should likewise decrease.

Rituximab

It should be noted that during treatment with rituximab about 50% of WM patients experience a transient increase in serum IgM levels – the IgM “flare” phenomenon. This flare occurs mostly during the first months of treatment but may persist for several months. If patients with baseline serum IgM level of 4000 mg/dl or greater have not had plasmapheresis prior to treatment, they may experience bleeding from their nose or gums during this period for the same reasons they had the bleeding initially.

Other adverse reactions to rituximab may be swelling of the lips, tongue, face, and throat during infusion. Severe mouth and skin reactions (Stevens-Johnson syndrome) have also been reported during treatment with rituximab. Tell your medical team right away if you experience red, swollen, peeling or blistered skin; or sores or ulcers on your skin, lips, or in your mouth.

Ibrutinib

Ibrutinib is a targeted therapy and inhibitor of an enzyme in the B-cell signaling pathway called Bruton's tyrosine kinase (BTK). Historically there was a strong rationale to begin testing this drug in WM patients because BTK is activated by the MYD88 L265P gene mutation found in 90-95% of WM patients.

Treatment-related side effects of ibrutinib include low white cell count (neutropenia), low platelet count (thrombocytopenia), post-procedural bleeding, ulcers, sores or white spots in the mouth (mucositis), nausea and vomiting, and dry mouth (xerostomia), among others.

Dental Considerations, cont. on page 26



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PRESIDENT'S CORNER



News You'll Want to Read

Do you sometimes find yourself dreading to read or watch the news? Does it seem to be too strife-driven and combative, no matter where you sit on the political spectrum? Well, come to Wally World and read the Good News You Can Use from the world of WM. There's a lot of good news to report.

We've strengthened the IWMF Board and Office to serve you better.

Since November 2016, we've added three new Board members: Dr. Linda Nelson as Publications Chair (See her cover article on page 1.); Beverly Docteur, Treasurer and Secretary, who is putting her many years of non-profit experience to work for us; and Lisa Wise, LIFELINE Chair, who is expanding our LIFELINE service.



The IWMF Sarasota Office Staff (from l. to r.): Jennifer Silva, Operations Manager; Karen Long, Marketing & Development Assistant; Sara McKinnie, Partner & Meeting Coordinator; Robin Tucker, Accountant; Brian Miller, Major Gifts Officer.

Since February 2017, we've added Jennifer Silva as Operations Manager at the IWMF Office as well as Karen Long, Robin Tucker, and Brian Miller. If you need help, contact our Office at 941-927-4963 or office@iwmf.com. They are a wonderfully supportive and capable group.

We've committed a record \$2.2M to new research projects to help us have better, more effective treatments and ultimately a cure.

This includes five new research projects from the IWMF-Leukemia & Lymphoma Society (LLS) Strategic Research Roadmap Initiative plus a specific project on amyloidosis in WM, funded entirely by a single donor. See the article on page 15 entitled "The Elting Family Fundraising Initiative" to learn how we were able to fund so many projects.

We now have 13 active research projects totaling over \$4.7M funded by WMers just like you and me. Importantly, we have the best minds across the globe working on our orphan disease with current projects in Germany, Spain, the Netherlands, Italy, the UK, Massachusetts, Connecticut, Missouri, Minnesota and California. Coupled with the Australians working on the WhiMSICAL database (see page 21), it means the sun never sets on WM research efforts. We're on this disease 24/7. Pretty cool, huh?

We're continuing to build on this research success.

The next IWMF-LLS Strategic Research Roadmap meeting will occur in New York City on October 14-15, 2017. For two days, 15 to 20 of the smartest researchers in the world will meet to discuss where we go next in our search for a cure. Dr. Lee Greenberger, Chief Scientific Officer of LLS, will chair the meeting. Following this meeting, we will issue a new Request for Proposals (RFP) in November for new research projects we'll initiate in 2018.

We've added 6 new partners in 2017 to enhance our capabilities.

Go to www.iwmf.com/about-us/partners to learn how each of our partners can help you. For example:

NCCN (National Comprehensive Cancer Network) has Patient Guidelines for WM.¹

Lab Tests Online gives help in deciphering your lab tests.²

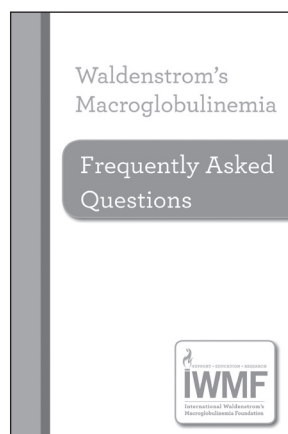
Triage Cancer offers a Cancer Finances toolkit.³

PAN Foundation gives co-pay assistance (only for those living in the US). Find out if you qualify.⁴

We've added new Member Services to help you better understand WM and your treatment options.

Videos: If you missed the hugely successful 2017 Patient Educational Forum in Phoenix or even if you were there, I have good news. All of the videos are available.⁵ Take a look!

A new FAQ (Frequently Asked Questions) booklet and a revised Medical Tests booklet are now available.⁶ The new FAQ booklet is available in seven languages: English, Spanish, French, German, Italian, traditional Chinese, and simplified Chinese. Best of all, it is written in easy-to-understand language. It's worth a review by everyone!



Cover of the recently published IWMF FAQ booklet.

President's Corner, cont. on page 4

A **joint webinar** with CancerCare entitled “What’s New in the Treatment of WM,” featuring Dr. Jorge Castillo of Dana-Farber Cancer Institute and Dr. Jeffrey Matous of the Colorado Blood Cancer Institute, occurred on October 4. If you missed it or if you want to listen to it again, visit iwmf.com to find the link where you can listen to this wonderful session any time you wish.

IWMF Connect: If you haven’t joined the 2,000 WMers worldwide who are sharing and learning from each other, go to our website and join today.⁷ You’ll be amazed at what you can learn when you connect with your fellow WMers.

The International WhiMSICAL Patient Database

The international WhiMSICAL patient database is up and running. The researchers in Australia hope to report their preliminary results (based upon the data provided by the first 200 WMers to register) at the annual meeting of the American Society of Hematology (ASH), slated for December in Atlanta. Since the ultimate goal is 1000+ members, we need **you** to enter your data.⁸ Please join today.

We’ll all be glad you did! I hope you found this to be good, real news you could use. Go read the rest of the *Torch* but come back to this article and put some of this good news to use for you! Use the links listed in the footnotes to help you.

Stay informed, focus on the good news, and stay well.
Carl

- ¹ <https://www.nccn.org/patients/guidelines/waldenstroms/files/assets/basic-html/page-1.html#>
- ² <https://labtestsonline.org/>
- ³ www.cancerfinances.org/toolkit/
- ⁴ www.panfoundation.org
- ⁵ <https://www.iwmf.com/media-library/videos/educational-forum-videos>
- ⁶ <https://www.iwmf.com/media-library/iwmf-publication>
- ⁷ <https://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums>
- ⁸ www.iwmf.com/news-and-events/news/new-global-patient-database-wm-%E2%80%93-your-help-needed

CELEBRATING OLA FERLA

COMPILED BY ALICE RIGINOS, *TORCH* EDITOR



Ola enjoys tea in the company of friends.

On June 9, 2017, IWMF member Ola Ferla celebrated her 100th birthday. In her honor a small party was held in the Smilow Cancer Hospital Apheresis unit of the Yale New Haven Hospital where Ola is treated every three weeks under the care of Dr. Alfred I. Lee of the Yale School of Medicine. At the celebration, a cannoli cake baked by her primary nurse, Anna Milani, RN, was served to staff members and physicians. Other guests included Ola’s daughter, Sue Ferla, and Ola’s friend, Phyllis Sturtevant. All joined in singing “Happy Birthday.”

It is not longevity alone that makes the life that Ola Ferla has lived for a full century so remarkable. Equally remarkable are the determination and courage she has displayed, beginning with her service as an Army corps nurse during World War II and continuing to today’s challenge of living with Waldenstrom’s macroglobulinemia, diagnosed twelve years ago.

Ola Krasnoselsky Ferla and her three siblings grew up in Ashfield, Massachusetts, on the farm of their parents, Ukranian immigrants who spoke little English. It was, notes Sue Ferla, quite remarkable that all four children went to college. Ola, who was selected Valedictorian of her high school class, attended the Hartford Hospital Nursing School. Following graduation, she achieved the highest score on the Connecticut Nursing State Board examination. Today she is the sole surviving member of her class.

A young Army nurse assigned to overseas duty in World War II, Ola spent her first year abroad at the 316th Station Hospital caring for the 1,200 troops stationed in Devon, England, who were in training for an invasion of occupied France by sea. However, once training was complete, the date for the invasion of the Normandy coast (the infamous D-Day) was not declared for another year. It was an anxious time for all

Celebrating Ola Ferla, cont. on page 5

involved, trying to keep preparations at the peak of readiness. There was, however, a sense of adventure among the young soldiers and nurses stationed at Devon. Ola today recalls the night-time walks out of camp onto the moor and other exploits involving her friend Vera, who flew planes to the front line and occasionally took Ola along (although strictly against the rules!). And Ola still remembers her overseas boyfriends, including one who did not survive the war.

When the invasion finally took place, Ola and other nurses, as well as Army medical officers, were sent ahead to Prestwick, Scotland, where preparations were in place to receive the wounded. Caring for those who survived one of World War II's bloodiest battles required great courage and determination on the part of the nurses. Bandaging up amputees and other severely wounded survivors, then administering morphine for the flight back to the states, comprised the daily routine. Ola can still remember with emotion the extreme cases that affected her deeply.

Returning to Hartford at the end of her service, Ola renewed contact with her future husband, S. Joseph Ferla, whom she had met before the war, after her graduation from nursing school. The war led Joe to Africa as it had taken Ola to Europe, and they corresponded for its duration. Joe, however, was badly wounded at Anzio, Italy. First his ammunition belt was hit by fire on the battlefield, he himself was next struck by shrapnel, and finally no less than 21 bullets from a machine gun rained down on him. His rescue and immediate surgery were nothing short of miraculous. Ola speaks of Joe as "a very gutsy man" who returned to the states and recovered in hospital. Two years later, following Joe's recovery, they were married in 1945 in St. Joseph's Cathedral in Hartford. Ola eventually put nursing aside to care for her children and husband. They had been married for forty-three years when Joe passed away.

A second time of challenge began twelve years ago when blood work, done prior to a knee replacement, led to the diagnosis of WM. Five years of watch and wait followed. When treatment was eventually required, Ola did not tolerate the standard chemotherapeutic drugs very well. For the past year plasmapheresis has been her only treatment.



Ola's 100th birthday was celebrated at Yale New Haven Hospital with a cake and a chorus of well wishers.

How does this former army nurse take to the role of patient? Sue Ferla reports today that her mother's training as nurse "has never left her." Nurse Ferla reviews every procedure with her medical team. "She counts the bottles, she asks the weight in grams of every drug administered. She wants to know exactly what is in the pill box." Clearly, she keeps her medical team on their toes.

This courageous and determined nurse, now WM patient, sets a very high standard for all of us!

The following sources provided information for this article:

*-Erica Schmitt, "The Good Fight," Connecticut **PRIME TIME**, May 2017, pages A6-A7.*

This article is based on the interview with Ola Ferla by World War II historian Aaron Elson.

- "Inspiring patient gives new meaning to term 'medical history,'" The Bulletin: The Newsletter of Yale New Haven Hospital, July 13, 2017, page 1.

Thanks are due to Sue Ferla for providing details of her mother's younger days as well as her sharp and spirited presence at 100.

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

USING ADVANCE MEDICAL DIRECTIVES TO ENSURE YOUR END OF LIFE TREATMENT CHOICES ARE HONORED

JUDITH K. SCHWARZ, PHD, RN



Judith K. Schwarz, RN, PhD

Judith Schwarz is a nationally and internationally known writer and speaker on advance directives and other end of life issues. These topics have not been previously addressed in the Torch, and we are fortunate to have such an experienced voice open the discussion.

I didn't know much about Waldenstrom's macroglobulinemia (WM)

before reading the April 2017 issue of the *Torch* – despite having a dear friend who was diagnosed with WM more than 12 years ago. She doesn't speak much about her disease, and, until recently, I didn't know enough about it to ask questions. What we do talk about, however, are her end of life concerns, wishes, and values. We are old friends after all – plus, this is my field of expertise. I am the Clinical Director of a not-for-profit end of life advocacy and support organization. I spend my professional time talking to folks diagnosed with incurable and progressive or terminal illnesses and their families about their end of life concerns, fears, and values.

I would like to start this article about advance directives and planning for life's end by summarizing my “take away” from the wealth of information provided in the Spring *Torch* issue. All the articles in the *Torch* were exceptionally clear and informative and helped me to understand what WM is (Dr. Morie Gertz), how people live with it (Alice Riginos), and how people share and learn from each other in support groups and via the Internet (support group news from Belgium). From my perspective, in Dr. Gertz's article it was the age of onset (WM is typically diagnosed at 60 or 70), the long “survival path,” and the likelihood that those with WM will die of some other disease or cause that focused my attention and to which I will subsequently return. I also appreciated his succinct definition: he called it a rare form of malignant lymphoma that is currently incurable but very treatable.

What I was most struck by in Alice Riginos' description of her almost 14 year journey with this disease was her statement that she had lived a “normal” life that was periodically put on hold for a round of treatment. In her case she has had 5 such life-interrupting experiences. She added that, in each case, “we are impatient for treatment to be over and to return to our own daily rhythms of life.” She also added the cautionary note that “no promises can be made regarding the outcome of treatment.”

And finally, the report from the West Flanders region of Belgium which described a symposium during the spring of 2016 that was followed by a number of regional events around the country in the fall. At the symposium, they addressed what was called a “challenging, yet rather obvious, topic: With the End of Life in Sight.” Apparently, even in Belgium where euthanasia is openly discussed and practiced, it was somewhat unusual for a group of people with WM to publicly discuss their wishes and concerns about the circumstances of dying. One thing most of the Belgian attendees agreed upon was their desire to die at home. Subsequent meetings addressed the benefits of palliative care and the importance of respect for the patient's right to be self-determining.

We know that most Americans strongly agree with the desire to die at home, surrounded by familiar objects and loved ones. But what I also know is that realizing such a desire takes “advance” planning and discussions with family members, caregivers, and clinicians. Only about 30% of adult Americans have completed some form of advance medical directive. That means that family members or other loved ones of the remaining 70% may be required to make very difficult treatment choices – often under the most emotionally difficult circumstances – in the waiting room outside a hospital Intensive Care Unit when doctors ask what they should do!

Returning to what I found particularly relevant about those living with WM, the following facts stand out: WM patients tend to be elderly when first diagnosed and often spend the next decade or two fighting the disease's symptoms, which tend to ebb and wane for unknown reasons. And patients will likely die of some other disease or cause. If you spend much time and energy fighting against death by a known but wily disease, you may find it particularly difficult to consider death as anything but an enemy to be fought fiercely – forever. The problem with that approach is that death can become a taboo subject – maybe “bad karma” to even mention such a topic – and certainly not anything one would want to plan for. At the risk of sounding banal, it must be noted that death is not optional for any of us, and some deaths are definitely worse than others.

What I propose to do next is provide a brief overview of the various documents most often used to effectively plan for how one wishes to be treated when one is unable to participate in treatment decisions. I will then summarize some of the important life-prolonging interventions that folks living with an incurable and progressive disease ought to consider when completing an advance directive.

Using Advance Medical, cont. on page 7

“Advance directive” is an umbrella term for the two kinds of documents frequently used to indicate your wishes about treatment when you cannot participate in health care discussions due to a temporary or permanent loss of decision-making capacity. One is an *appointment* directive – called a durable power for health care (DPAHC) or a health care proxy, and the other is a *written* directive – commonly known as a living will. An appointment directive is the preferred form and will be discussed first. Each state passes health care legislation describing the advance directive “honored” in that state. The forms can be obtained online by going to the state’s department of health and seeking information about advance directive forms. Forms can also be obtained in physicians’ offices or in hospitals and community health clinics. Although most states now tend to honor each other’s documents, you ought to have a state-recognized document for each state in which you spend substantial time each year. It is also important to note that the instructions in an advance directive – written or appointment – become “operational” only after the person who completed the document loses decision - making capacity. Until that time, it is the patient who decides what will be done to himself or herself.

A DPAHC or health care proxy is the preferred document because the appointed person can interact with members of the health care team and share the patient’s long-held values and preferences regarding end of life conditions and treatments. However it must be said that this document is only as good as the discussion that has preceded the completion of the form. Your appointed agent must know what you fear and wish for – along with medical conditions that you would find intolerable. These can be difficult conversations to have – at least in the beginning – but having honest, complete (and regular) conversations about your wishes is a *gift* you give to your loved ones. Doing so will prevent the horrible situation where loved ones do not know what choice you would want when the physicians turn to them for guidance.

The role of the agent is to speak for the patient who is now silent. In other words, to bring her or his voice into the treatment discussion with clinicians and to choose as that person would if they could participate in the discussion. It can be hard to decide to stop a life-prolonging intervention – *even when* you know that the now-silent person would not want it continued. Yet it can be emotionally devastating to consider such a decision when you do not know what the incapacitated person would want. It can also be very difficult to make treatment decisions under conditions of clinical uncertainty. Physicians often are unable to be precise in either their prognostications or their predictions about whether a particular intervention will “succeed.” Often a good approach is to agree to a trial of treatment – say two weeks – and then have another meeting to determine whether the treatment worked or should be stopped. What most people fear is remaining unconscious, unresponsive, and attached to life-prolonging machinery indefinitely, without hope of

improvement or recovery. A trial of treatment, for example 2 weeks of aggressive pulmonary care, can be followed by a clinical assessment of the efficacy of such treatment and then an “informed” decision about whether or not to withdraw the ventilator.

When having a discussion with an agent about treatment values, you should also include your wishes about frequently used life-sustaining interventions such as feeding tubes, cardiac pace makers, and mechanical ventilation. Some people who feel strongly about not wanting their dying to be prolonged might also instruct their health care agent to withhold “simple” treatments like antibiotics or blood transfusions while requesting maximum pain relief even if doing so might secondarily hasten dying.

Living wills are documents completed by a person who stipulates in writing the end of life treatments they wish to receive or avoid under particular medical circumstances. One of the challenges of these documents is to include all interventions and conditions about which the person cares deeply. Plus, there are certain medical circumstances that must occur before such documents are honored; each state includes any pre-existing conditions in their health care legislation. Some of those circumstances include a diagnosis of terminal illness, or permanent unconsciousness.

All too often written directives become lost, or are misplaced in an emergency, or ignored by clinicians who find the directions clinically inappropriate for the circumstances or condition with which the patient presents in an emergency room. A completed living will may be better than nothing as a general indication of end of life values. It can also be the case that some individuals may have out-lived their family members and friends, or don’t feel they have anyone they can ask or trust to be their health care agent. Yet, they are not the preferred mechanism for ensuring that your treatment choices will be honored when capacity is lost.

Two final sorts of directives must be quickly mentioned. For hospitalized patients, a Do Not Resuscitate Order (DNR) is increasingly chosen by elderly people who want to avoid the trauma of attempts at cardio-pulmonary resuscitation along with intubation and mechanical ventilation in the event they stop breathing or have a cardiac arrhythmia. What we know is that such resuscitation attempts rarely are successful, particularly in frail, elderly people. By “successful” I mean that the person rarely attains their pre-arrest cognitive status and often is left with brain damage *and* broken ribs following the attempt.

Once the person leaves the hospital they must get their physician to write an “Out of Hospital Do Not Resuscitate Order” as that is the only document that Emergency Medical Technicians (EMTs) recognize when called to a home by a 911 call. EMTs are otherwise required by law to attempt resuscitation, regardless of what the family may request to the

contrary. This medical order should be taped on the outside of the refrigerator.

The second document that is being increasingly recommended for use by those who have become frail, elderly, and ill and are getting “close” to death – two years or so as a physician guesstimate – is a Medical Orders for Life Sustaining Treatment (MOLST), sometimes called a POST (Physicians Orders for Life Sustaining Treatment). These documents combine all of the other advance instructions in a DPAHC, a living will, and an Out of Hospital DNR, along with additional wishes to not be transported to the hospital and to request maximum pain relief. These patient wishes are then converted to a physician’s medical orders. Doing so increases the likelihood they will be honored by other physicians and clinicians. These medical orders are often printed on brightly colored paper so they are less likely to be misplaced.

Like all such important documents, patients at home are instructed to make many copies, give them to their health care agent, family members, and physicians, *and* tape the MOLST form to the outside of the refrigerator. That is where EMTs are trained to look for them.

In conclusion, I encourage all of you who have taken the time to read through to the end of this article to take the *next* step – take steps to begin the process of talking to your loved ones about your end of life choices, fears, goals, and concerns. Then document those wishes in your state’s recognized advance directive. These documents are not about giving up but affirmatively taking steps to be sure that your choices are the ones that will drive future decisions in the event that you cannot participate directly in treatment decisions. Your loved ones will be grateful that you cared so much for their feelings that you relieved them of the awful burden of not knowing what to do when treatment decisions must be made.

IN THE TORCHLIGHT

ALI HANDAL: MUSIC IN EVERY MOMENT

BY PETER DENARDIS, IWMF TRUSTEE



Ali Handal has a new album and will soon be on tour!

Every so often, life strikes dissonant chords. One can either choose to be consumed by their harshness and tension or channel them to produce music amidst the discord. Ali Handal is committed to making music, in both her personal and professional lives.

Ali is an accomplished guitarist and singer – songwriter (all of you who attended the Ed Forum in 2015 and listened to her keynote performance can

attest to her amazing talents). Ali has pursued music in one form or another since she was a young girl. Her musical credits include singing on Neil Young’s “Living With War” album and performing onstage with Paul Williams. She recently released her fourth album, “That’s What She Said,” on a major record label. One song in particular – “Let Go” – may resonate with fellow WMers as it relates her feelings about being diagnosed with cancer.

Back in December 2013 her journey with WM began, after a physical exam was required for obtaining long-term care insurance. Ali and her husband had decided to do the physical together. While she cautioned her husband to get in shape in

advance of the exam, she never thought she would be the one who would be denied insurance. The exam showed she had an unusually elevated level of protein in her blood and very low hemoglobin. So certain was Ali of her good health that she asked for a re-run of the tests. The results were the same.

Apparently, the fatigue she had been feeling for the past several months was due to something more serious than her busy work schedule. Further testing found her IgM to be 7,300 mg/dl – significantly above the normal range. So, at age 44, due to her blood test results and ongoing symptoms, it was decided that she would undergo a treatment regimen of a combination of bendamustine and rituximab over a four-month period.

Ali was no stranger to discordant notes in her life. She lost a favorite uncle in a car crash when she was 15 and had lost her mother-in-law to breast cancer just a couple of years before her own diagnosis. Wise beyond her years, she realized as a teenager that you can’t take any day for granted and vowed never to do so.

Ali’s husband is Andrew Goldenhersh, a renowned magician who performs around the world. Andrew was Ali’s strong supporter. His presence, providing humor, comfort, and “just being there” helped her deal with whatever the treatments would bring her way. She also had a strong family support system, and the WM diagnosis brought her family even

In the Torchlight, cont. on page 9

closer together. Her mother, a 10-year lymphoma survivor at the time, flew down to Los Angeles to help Ali through all of her chemo treatments. Her father brought her to Dr. Jorge Castillo for a second opinion and accompanied her to the IWMF Ed Forums (author's note: I recall her first Ed Forum – Ali was the “classic” first-timer, a bit scared, a good bit overwhelmed, a good bit worried; but her father approached each speaker after each talk to ask questions and seek advice for his daughter; it was important to him to take advantage of that golden opportunity to speak to and confer with the noted experts in WM research and treatment). Ali's two younger sisters both provided comfort and support throughout her WM journey.

The treatment regimen produced the desired results, and while she did have some of the usual side effects, they did not stop her from pursuing her life-long passion of writing and performing music. Her IgM went down to its lowest level of 524 mg/dl after treatment, and she was able to get three good years of remission out of it.

Ali did try attending a couple of cancer support groups near her but found them to be more depressing than helpful. In time, her “go to” source for obtaining comfort and support from fellow cancer survivors became the IWMF via the Ed Forums, LIFELINE, IWMF Connect discussion list, and IWMF Facebook pages. She encourages everyone to “use the resources...reach out to people...connect with them...especially people who are of a similar age, experience, and condition.” Her most vibrant memory of her first Ed Forum is of the late Ron Yee (IWMF Lifetime Achievement Award recipient in 2017) providing words of advice and comfort during his “First Timer's” presentation. He gave her the courage to realize that WM is not a death sentence and that one could live life fully despite the diagnosis. She also came to learn that there **are** experts in WM who are very approachable, providing valuable advice, but, alternatively, there are no real “right” opinions. Each patient has his or her own particular health conditions to contend with, his or her own variant of WM, and, ultimately, has to choose from a variety of possible treatment options, each of which can provide a desired result but also comes with its own set of side effects.

In true “Ali style,” she didn't allow her diagnosis or treatment to hold her back – she continued to write music and perform, and she did not feel animosity towards her cancer. “It's a part of my body,” she says, “it happens to people.” In fact she's happy to educate people about her disease and how to deal with it. She finds encouragement in knowing that “lots of people are living amazingly full lives with incurable diseases.”

Over the years, Ali shares, her approach to life hasn't really changed. She continues to love music, pursuing her performing career and striving not to take anything for granted. She feels incredibly supported and fortunate to have her family by her side whenever a dissonant chord strikes.

When asked what her advice to fellow WMers would be, given that she's now a “WM veteran,” Ali offered this: “Continue to make music in your life. Do your best to appreciate every moment, big and small.”

After all, dissonant chords can also make exquisite music, if you let them.

* * * * *

Ali lives in Sherman Oaks, California, and performs throughout the world, continuing to make beautiful music – personally with her family and friends and professionally with her songs and albums. Her new record “That's What She Said” is available at <http://shop.alihandal.com>, as well as iTunes and Amazon.

Performance at 2015 Ed Forum: <https://www.youtube.com/watch?v=k1BgtHjK-uU>

To check on Ali's upcoming touring schedule: <http://AliHandal.com>

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

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Dana-Farber Cancer Institute to Open Clinical Trial of Daratumumab for WM – Dana-Farber Cancer Institute plans to open a Phase II clinical trial of daratumumab (Darzalex) for relapsed/refractory WM patients. Daratumumab is a human monoclonal antibody that targets the CD38 cell surface antigen and is approved by the US Food and Drug Administration for treatment of relapsed multiple myeloma. The identifier number for this trial on www.clinicaltrials.gov is NCT03187262.

Update Presented of BGB-3111 Phase I Trial Results in WM – Updated data from the Phase I study of the BTK inhibitor BGB-3111 in WM was presented during the 14th International Conference on Malignant Lymphoma in Lugano, Switzerland. The 42 patients who are now evaluable have a median follow-up time of 12.3 months and demonstrate an overall response rate of 90%, with a major response rate of 76% and a very good partial response rate of 43%. The most frequent adverse events were bruising, petechiae (pinpoint reddish spots on the skin due to bleeding) upper respiratory tract infection, constipation, diarrhea, nosebleed, nausea, cough, anemia, headache, neutropenia (low neutrophils), and rash. There were 3 cases of atrial fibrillation, and 2 patients had disease progression during treatment. This Phase I trial has been conducted in Australia, New Zealand, South Korea, and the US. BGB-3111 is a product of BeiGene, Ltd., and is currently being evaluated in a Phase III study of WM, comparing the drug to ibrutinib. The identifier number of the Phase III trial on www.clinicaltrials.gov is NCT03053440.

Article Discusses Occurrence and Significance of TP53 Mutation in WM – French researchers published an article in the journal *Clinical Cancer Research* that discusses the significance of the TP53 mutation in WM. TP53 is a tumor suppressor gene, and mutations in TP53 are associated with worse outcomes in most B-cell lymphomas. These researchers genetically sequenced 125 WM and 10 IgM-MGUS patients. Overall, alterations in TP53 were detected in 11.2% of WM and were absent in IgM-MGUS. No correlation with CXCR4 mutations was observed. WM patients with TP53 alterations had a significantly shorter overall survival, particularly when they were in symptomatic disease status. The researchers suggest that specific treatment for WM patients with TP53 alterations should be studied.

French Researchers Analyze Data on Transformation of WM – The French Innovative Leukemia Organization (FILO) has presented a multicenter retrospective analysis of 77 cases of transformed WM. Transformation to the aggressive lymphoma called diffuse large B-cell lymphoma (DLBCL) is a rare and poorly reported complication of WM. The results of this study indicated a median time from WM diagnosis to DLBCL transformation of 4.6 years, and 16

patients (21%) had never been treated for WM. Extranodal (outside of the lymph node) disease sites were observed in 91% of patients, with a rather high incidence of central nervous system, skin, or testicular involvement. First-line treatment for transformation was R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, prednisone) in 85% of patients. The overall response rate after treatment was 61%, and the median overall survival was 16 months. A time to transformation above 5 years and an elevated LDH (lactate dehydrogenase) were associated with a worse outcome. Based on these findings, the researchers suggest that the possibility of transformation should be considered in WM patients presenting with extranodal involvement, elevated LDH, and constitutional symptoms (recurring fever, night sweats, weight loss, fatigue) and should prompt a biopsy.

Clinical Study Looks at BGB-3111 Combined with Gazyva for Several Lymphomas – Data were also presented at the 14th International Conference on Malignant Lymphoma from a Phase I study of BGB-3111 combined with the anti-CD20 monoclonal antibody obinutuzumab (Gazyva) in patients with chronic lymphocytic leukemia/small lymphocytic lymphoma and follicular lymphoma. High overall response rates were observed, thereby supporting preclinical indications that BGB-3111 combines well with monoclonal antibodies.

US FDA Grants Breakthrough Therapy Status to Acalabrutinib for Mantle Cell Lymphoma – Acalabrutinib, also known as ACP-196, has received Breakthrough Therapy Designation from the US Food and Drug Administration for the treatment of relapsed/refractory mantle cell lymphoma. Acalabrutinib is a BTK inhibitor developed by Acerta Pharma and is being tested in clinical trials of other lymphomas, including WM. It reportedly is more potent and has a less toxic side effect profile than ibrutinib (Imbruvica). This new status is expected to expedite further development and regulatory review of the drug.

Ibrutinib Receives Approvals for Two Additional Conditions – The US Food and Drug Administration (FDA) has approved ibrutinib (Imbruvica) for the treatment of adult patients with chronic graft vs. host disease (cGVHD) following allogeneic stem cell transplant therapy. cGVHD remains a serious complication of stem cell transplant from partially matched donors because the donor immune cells attack the recipient's tissues and organs. The trial upon which this approval was based showed that 67% of the 42 patients receiving ibrutinib responded, including 21% complete responses. The patients in the trial had failed to respond to other therapies, including first-line corticosteroid treatment. Adverse reactions, the most common being fatigue and

Medical News Roundup, cont. on page 11

pneumonia, led 24% of patients to discontinue ibrutinib for cGVHD...meanwhile, ibrutinib was also recently approved for marginal zone lymphoma patients who have received one or more prior therapies, including at least one anti-CD20 monoclonal antibody. The approval was based on a single Phase II study and applies to three marginal zone lymphoma subtypes: mucosa-associated lymphoid tissue, nodal, and splenic. All patients received 560 mg once daily; the overall response rate was 46%, and the median time to response was 4.5 months. The most common adverse effects were diarrhea, anemia, nausea, thrombocytopenia (low platelets), peripheral edema, cough, joint pain, shortness of breath, and upper respiratory tract infection. Ibrutinib now becomes the first drug approved by the FDA for marginal zone lymphoma.

Another Biosimilar to Rituximab Approved in European Union – Another biosimilar to rituximab (Rituxan or Mabthera) has been approved in Europe for several types of non-Hodgkin's lymphoma and chronic lymphocytic leukemia. This one, called Rixathon, is manufactured by Sandoz, a division of Novartis. The company plans to seek FDA approval in the US later this year. A biosimilar is an almost identical copy of an original biologic medical product manufactured by a different company, is an officially approved version of the original product, and can be manufactured when the original product's patent expires. Roche's patent in Europe for rituximab expired in late 2013.

Test Predicts Risk for AFib Development in CLL Patients on Ibrutinib – A presentation at the annual meeting of the International Workshop on Chronic Lymphocytic Leukemia (CLL) reported on a moderately specific and sensitive test that independently predicts risk for atrial fibrillation (AFib) in CLL patients on ibrutinib (Imbruvica). This retrospective study, presented by the Abramson Cancer Center at the University of Pennsylvania, suggests that the presence of a left atrial abnormality (LAA) before ibrutinib therapy is associated with a 9 times increased risk of subsequently developing AFib while on ibrutinib. Although verification is suggested through prospective trials, this presentation reported that routinely checking for left atrial abnormality by electrocardiogram (ECG) prior to starting ibrutinib is a means of identifying a patient subgroup that is prone to developing AFib on the drug. This subgroup would benefit from increased monitoring and proactive intervention strategies to reduce complications should AFib subsequently develop.

Oral Proteasome Inhibitor Ixazomib Used to Treat AL Amyloidosis in Multiple Myeloma Patients – Investigators recently published data in the journal *Blood* from a Phase I/II clinical trial of the oral proteasome inhibitor ixazomib (Ninlaro) for the treatment of multiple myeloma patients with relapsed or refractory amyloid light-chain (AL) amyloidosis. This rare condition, which can also occur in WM, results when the free light chains produced by the clonal B-cells develop into an abnormally folded protein called amyloid

that cannot be broken down. Amyloid can form deposits in different organs, most commonly the kidneys in WM patients, and cause serious damage. In this study, ixazomib was given weekly for up to 12 cycles, and dexamethasone was added after 3 cycles in those patients who had not yet responded. Approximately half of the 27 patients in the study achieved responses with ixazomib alone or in combination with dexamethasone, including some patients who had been previously treated with bortezomib (Velcade). Grade 3 (moderate to severe) diarrhea, rash, and thrombocytopenia (low platelets) occurred in 11% of patients, but no peripheral neuropathy was observed. A Phase III trial of ixazomib plus dexamethasone in AL amyloidosis is currently in progress.

Analysis Looks at Central Nervous System Involvement in Low Grade B-Cell Lymphomas – An analysis of the National Cancer Database looked at the distribution, demographics, and outcomes of patients with low grade B-cell lymphomas involving the central nervous system (CNS). This database represents approximately 70% of cancer cases in the US. The analysis, performed by the Mayo Clinic in Rochester, MN, and presented at the 2017 American Society of Clinical Oncology Annual Meeting, identified 475 such cases from 2004-2013. In this group, the median age at diagnosis was 58 years, and the majority of cases were female (56%), Caucasian non-Hispanic (72%), and with no comorbidities (74%). The brain itself was the most common site of involvement, followed by the spinal cord and the meninges (the membranes covering the brain and spinal cord). Follicular lymphoma (FL) at 48% was the most common low grade lymphoma overall, followed by marginal zone lymphoma (MZL) at 37%, small lymphocytic lymphoma (SLL) at 8%, and lymphoplasmacytic lymphoma (LPL) at 7%. [Note: WM is by far the most common lymphoplasmacytic lymphoma.] Survival was not influenced by sex, race, or year of diagnosis; it was, however, influenced by age at diagnosis, comorbidities, the type of lymphoma and the site of disease. Five-year overall survival by type of lymphoma was 83% for MZL, 75% for FL, 56% for LPL, and 50% for SLL, and by site of disease was 89% for spinal cord, 78% for meninges, and 63% for brain.

FDA Approves First Gene Therapy in the US – The US Food and Drug Administration has just approved the first gene therapy drug, called Kymriah. Kymriah is a type of immunotherapy called CAR T-cell therapy, and it has been approved for the treatment of pediatric acute lymphoblastic leukemia (ALL). During CAR T-cell therapy, T-cells are collected from a patient via apheresis (a process similar to plasmapheresis). They are sent to a laboratory where they are genetically engineered to produce chimeric antigen receptors (CARs), which are proteins that allow the T-cells to recognize an antigen on the patient's tumor cells – in the case of Kymriah, the antigen is CD19, expressed on B-cells. The re-engineered T-cells are known as CAR T-cells. The number of these cells is expanded by growing them in the laboratory

in the millions, following which they are re-introduced into the patient's bloodstream. The CARs on the T-cell surface recognize tumor cells in the patient's body and attack them; they may remain in the body long after the infusion has been completed and can guard against recurrence, frequently resulting in long-term remissions. In a trial of 63 pediatric ALL patients treated with Kymriah, 83% were in remission after 3 months and 64% were still in remission after one year. One of the most common side effects of CAR T-cell therapy is called cytokine release syndrome, and it was seen in about 50% of patients in the Kymriah study. This syndrome is typically characterized by low blood pressure, fever, nausea, shortness of breath, and severe shaking chills and can lead to more serious consequences; it is thought to be due to a systemic inflammatory response to the release of chemical signals produced by the activated T-cells. Novartis, the maker of Kymriah, has priced the treatment at \$475,000, excluding the cost of hospital stays and supportive therapies. CAR T-cells are being studied in other types of blood cancers.

Promising CAR T-Cell Therapy Results Reported in Multiple Myeloma – A Chinese research study presented at the American Society of Clinical Oncology Annual Meeting discussed a trial of CAR T-cell therapy for the treatment of patients with relapsed or refractory multiple myeloma. Instead of using CAR T-cells targeting the CD19 antigen, this trial of 35 patients targeted the B-cell maturation protein (BCMA). The overall response rate was 100%; 33 of the 35 patients (94%) had clinical remission of their multiple myeloma, with either complete response or very good partial response occurring within 2 months of therapy. Five of these patients have been followed for more than 1 year, and all 5 remain in complete remission and are free of minimal residual disease. Cytokine release syndrome occurred in 85%; however, it was not life-threatening and there were no treatment-related deaths.

CAR T-Cell Therapy Also Studied in Chronic Lymphocytic Leukemia Patients – CAR T-cell therapy is also being studied in patients with chronic lymphocytic leukemia who were previously treated with ibrutinib (Imbruvica). The Phase I/II trial results, published in the *Journal of Clinical Oncology* by Fred Hutchinson Cancer Research Center, treated 24 patients. Four weeks after CAR T-cell infusion, the overall

response rate was 71%. Twenty patients (83%) developed cytokine release syndrome, while 8 patients (33%) developed neurotoxicity, which can include confusion, delirium, and hallucinations; neurotoxicity was reversible in all but one patient, who died.

FDA Grants Investigational New Drug Status to Engineered T-Cell Therapy Combined with Rituxan for NHL – The US Food and Drug Administration has granted Investigational New Drug status to the combination of ACTR707 and Rituxan for CD20-positive non-Hodgkin's lymphoma. ACTR707 was developed by Unum Therapeutics and is an engineered T-cell therapy that combines components of different human immune cells to improve their attack on cancer cells. It aims to overcome some of the limitations of other engineered T-cell therapies, such as CAR T-cells, and is intended to be used as a combination therapy with tumor-targeting monoclonal antibodies. The company plans a US-based, multicenter Phase I trial of the treatment to begin in the second half of 2017.

Phase II Trial Results Presented for Dual SYK/JAK Kinase Inhibitor Treatment in B-Cell Malignancies – Portola Pharmaceuticals Inc. presented interim data at the 14th International Conference of Malignant Lymphoma from its Phase IIA study evaluating cerdulatinib in patients with relapsed/refractory B-cell malignancies. Cerdulatinib is an oral inhibitor of the tyrosine kinases SYK and JAK, and its dual mode of action is anticipated to make it more effective. The partial response rates were 67% for chronic lymphocytic lymphoma/small lymphocytic lymphoma, 56% for follicular lymphoma, and 14% for marginal zone lymphoma and WM. Although the drug was generally well tolerated in most patients, 3 had severe adverse events that included infections and pancreatitis. The dose was subsequently reduced from 35 mg daily to 30 mg without compromising clinical activity.

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 Connect community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

FROM IWMF CONNECT

BY JACOB WEINTRAUB, MD

Summer is gone and we can reflect on the range of subjects discussed, at times heatedly, since July. As noted last time, the online discussion group has undergone some changes, including a change of name, and now is IWMF Connect. Almost everyone seems to have made the adjustment and been able to contribute when they want. We continue to post human interest stories, relevant articles, and other items to complement the more specific experiential discussions. Many subjects resurface following an absence of some time, while other subjects never seem to go away but are presented in a new light with new information to discuss.

HUMAN INTEREST ARTICLES

IWMF Connect Manager and IWMF Trustee **Peter DeNardis** posted links of general interest.

One article that drew a lot of praise for its relevance concerns the worry that a person's cancer will return, a concern common to all of us. The article presents some helpful advice on how to manage this particular anxiety.

<http://www.netdoctor.co.uk/healthy-living/a28612/fear-of-cancer-recurrence>

Peter posted a link to a website of a fellow cancer patient who has taken it upon himself to use his talents to develop comics about getting cancer and surviving it. An ongoing variety of situations are depicted, most of which we can relate to.

<http://cancerowl.com>

One other post from Peter was to an article about what to say to someone who has cancer. This article actually is a bit light-hearted with the author giving some of the best things anyone has ever said to her concerning her "cancerousness." It is a follow-up to her article about what not to say to someone with cancer, so be sure to follow the link within to also read her previous article.

<https://rethinkbreastcancer.com/cancer-is-crap-never-let-go-of-the-potato-what-to-say-when-someone-has-cancer>

A final post from Peter raises considerations about choosing an oncologist. This discussion has occurred in IWMF Connect in the past, but this article is a nice summary of what is very relevant. Most of us will recognize some of the factors we have considered when we first were diagnosed with WM. Other interesting articles appear there also.

<https://lymphomanewstoday.com/2017/08/17/>

Wanda H also posted links to several articles of general interest, including an article by Jessie Parks, a writer for the *Charleston City Paper*, about the psychologic impact of her mother being diagnosed with WM in 2015. I found this article relevant not only for people who have a family member diagnosed with WM, but also for any of us who have had a parent diagnosed with a chronic severe medical condition.

<https://patientworthy.com/2017/06/30/complicated-feelings-waldenstrom-macroglobulinemia>

Finally, Wanda also posted a link to an article about the cost of cancer treatment. This is about a young couple whose insurance was initially very limited, but, even after the husband landed a job with better benefits at a major university, the family was left with overwhelming bills related to diagnosis and treatment.

<http://www.npr.org/sections/health-shots/2017/01/10/542589232/widowed-early-a-cancer-doctor-writes-about-the-harm-of-medical-debt>

MEDICARE

This is a subject that comes up periodically as we age and people ask about which Medicare supplement plans work best.

Reggie A asked if anyone could suggest a Medicare plan that will pick up and cover Imbruvica (ibrutinib) treatment. He will be transitioning to Medicare from a private plan that has been expensive but has great coverage, including for Imbruvica.

The following replied to Reggie and outlined their experiences.

Ginger H reported that prescription medications come under Part D. For her, in Vermont, all the supplement plans would leave her with an annual cost of \$11,000 to 12,000 per year. Fortunately, she was accepted by the Johnson & Johnson Patient Assistance Foundation, which will help significantly with the cost of the med.

Amy B reported that she recently went on Medicare and has Part D. It cost \$3000 the first month and \$500 a month after that. She is "in the donut hole," but she is trying to get on her husband's health plan. She also suggested that there are patient assistance plans if one's income is low enough.

Steven D posted a link to the Johnson & Johnson Patient Assistance Foundation. The site does not list financial criteria but does list many of the drugs that are covered. He reported that after spending a total of \$4950, the monthly cost should be well under \$500 for WM.

<http://jjpaf.org>

Karen M suggested that after a person gets out of the donut hole (around \$4500), Medicare Part D pays all.

Clearly there is a lot of information to be considered in selecting Medicare supplement plans. A person will need to study the situation carefully before making choices. There are always people in the IWMF Connect family who are willing to share their experiences and understanding of the Medicare system, offering to help those "newly-turned-65-years-olds" in need of support and experience.

From IWMF Connect, cont. on page 14

VISCOSITY AND THE EYES

This is a subject that comes up periodically and is related to the potential for hyperviscosity in WM and its possible effect on the eyes.

Jane posted that her serum viscosity is 5.1. She had a retinal photo done which showed thickening of the retinal veins, plus two small hemorrhages. She has no other symptoms except for mild breathlessness on stairs. Jane is on watch-and-wait. Her hematologist suggested that, once her viscosity level comes down, the eyes will return to normal. She is trying to wait as long as possible before starting treatment and asked if it is reasonable to continue to monitor her eyes with monthly retinal photos.

Steven D suggested that Jane's viscosity is fairly high and wondered if there are specific criteria based on the condition of the retina for making a decision about treatment. He recommended obtaining an ophthalmologist's exam and opinion.

The same opinion was echoed by **Gerri W** and by **Barb H**. Barb reported she developed significant eye changes at viscosity of only 1.8 and was immediately started on treatment.

Dr. Maureen Hanley, optometrist, noted that not all viscosity changes in the eye will improve. If a person has had a central retinal vein occlusion, in most cases vision will not improve back to normal, although every case is different. Maureen added that with serum viscosity of 5.1 and no diabetes or hypertension, Jane may wish to get another opinion on whether to be treated. It also might be worthwhile to repeat testing the serum viscosity. Finally, Maureen cautioned that with the eye, a person can be "fine" one day and may even have a few small hemorrhages on the retina while vision is normal. Then, the next day, wake up with a massive vein occlusion and vision will be "counting fingers," with no significant improvement over time.

Dr. Tom Hoffmann supported this opinion. He stated that Jane should have treatment or plasmapheresis now and repeated the message that the eyes will not go back to normal if a calamity like vein occlusion occurs.

Jane posted a follow-up, reporting that she had recontacted her hematologist, who then proceeded to order a series of plasmaphereses while waiting for some additional testing.

PERIPHERAL NEUROPATHY

This, too, is a subject that has been discussed in the past. However, the topic of neuropathy always is very timely, given that new members join the discussion with new symptoms and questions about treatment.

Natalie asked if anyone's peripheral neuropathy (PN) worsens as IgM rises. Her husband's PN started in his feet and now has moved up to his thighs.

Carl G reported his PN has moved upward from his feet, now up to just above the ankle. He has been using only symptomatic treatment, a cream formula that contains gabapentin. Carl is trying to avoid using oral gabapentin.

Linda C posted that her husband has severe neuropathy in his right leg. He has been treated with Rituxan, fludarabine and also with R-CHOP (a standard regimen for non-Hodgkin lymphomas).

Jane posted that she has had PN since her diagnosis of WM 8 years ago. The PN actually led to the diagnosis of her WM. Her neuropathy is worse at night and has progressed over the years. Jane has been prescribed several different medications. She tried Lyrica, but that made her sick to her stomach. She currently is taking oxcarbazepine (Trileptal), and this takes the edge off the pain and makes the neuropathy tolerable. She had not seen this med mentioned before.

Betsy M mentioned that her neurologist recommended she take vitamin B12, and this has helped. However, many others responded that this treatment only helps if a person is documented to have vitamin B12 deficiency and that everyone should be tested for this before starting to take this vitamin.

Mike reported that he never has been tested for B12 level but has been told he has an "anti-MAG" neuropathy. His PN is not painful, but it is progressive and is at a point where walking is difficult.

Dr. Tom Hoffmann replied that if a person has a positive blood test for anti-MAG antibody, it is the cause of the PN. B12 is noted to be low in elderly people, especially over age 80 years, and also in people with a vegan diet.

Finally, **Suzanne O** reported that a Scandinavian group of WM patients was having a discussion about whether Rituxan causes PN. For several patients, PN has been associated with Rituxan treatment. Suzanne asked if there have been any studies showing the frequency to be much more than the 1/10,000 reported in the literature. She wondered about the accuracy of the reporting.

Dr. Jacob Weintraub, IWMF Connect Editor, suggested that it is likely that the frequency of PN caused by Rituxan is fairly small. The meds that have been shown to cause neuropathy usually show themselves fairly definitively. Perhaps the two best known are Velcade and vincristine (Oncovin; part of the CHOP regimen used mainly in other non-Hodgkin lymphomas). However, it is possible that the neuropathy is being caused by an IgM flare, which is well documented. The increased IgM from a flare can cause neuropathy. There may be studies ongoing to see what is the actual incidence of neuropathy from Rituxan, but we might not know the results of these studies until they are published. Dr. Weintraub added that there was a presentation at an IWMF Ed Forum several years ago by a neurologist with expertise in WM-related PN. He reported a clinical protocol using Rituxan to treat PN.

From IWMF Connect, cont. on page 15

This protocol involved Rituxan every other month for over two years and seemed to be effective.

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 and contribute. 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.

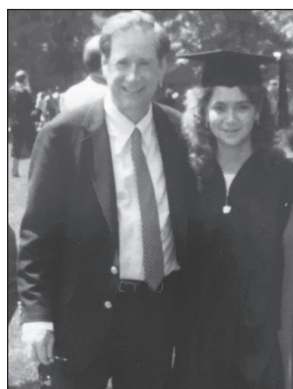
THE ELTING FAMILY FUNDRAISING INITIATIVE

BY MITCH ORFUSS

MEETING THE CHALLENGE

Everett (“Ev”) Elting is a happy man. A retired executive, he enjoyed a remarkable career as the President and CEO of the Canadian operations of a global advertising agency. At “age 81 and a half” (as he joyfully puts it), he is more grateful than ever for what he calls a “great life” in sunny California with his wife Joanne. Ev’s enthusiasm for life and health is immediately palpable, even infectious – even on a phone call. He is a man who wakes up every morning with the conscious question: “How can I get 24 hours of pleasure out of the day in front of me?” You immediately get the feeling that he always does!

Ev had been a lifelong tennis player, and a talented one. But upon entering his 70s, his knee for the first time started to slow him down on the tennis court. Undeterred, he kept playing until the pain worsened. Finally, he went to an orthopedist and was told it was time to have the knee replaced – a surgery that implicitly threatened to end Ev’s tennis days. There was no alternative but to move ahead with what had to be, so the knee was removed and replaced.



Ev Elting and his daughter
Liz before Waldenstrom’s.

Instead of being the end of the story, surgery was just the start. Ev’s extracted knee was sent off to a pathologist, who reported back to Ev’s orthopedic surgeon that the knee had evidence of...*blood cancer*. “The good news,” Ev told me, “is that my new knee is doing great. But the old knee had cancer.”

“After the unexpected call from my orthopedic surgeon, I realized I now had *two*

challenges – the one I expected and the one I didn’t. The one I fully anticipated was: How soon would my leg heal and get me back to tennis? Unfortunately for me, the answer was that my tennis days were probably over. Okay, I thought, I’ll play golf and get good at it! I’ll go to the gym and improve my overall strength and fitness! I’ll take 4-mile walks with my

wife! Life will not just continue without tennis – it will get even better.

“The unexpected challenge, however, was more concerning. It was also more urgent: to find out what cancer I had and what the implications were, a question that transcended whether I could play tennis again. I was, of course, completely ignorant, as most of us are until it happens, about blood cancer. But I knew that whatever I had could be serious. I was sent to a hematologist, who put me through all the necessary tests. The results came back and I learned that what I had was lymphoma. I couldn’t help but try to educate myself about lymphoma on the Internet. I thought I might have just a few years to live.

“That was more than six years ago, when I was 75, and I still felt well. In fact, terrific! Oh, I had some symptoms, of course, but luckily nothing that prompted me to think about treatment. And I was never sure if being a little out-of-breath on a long walk with Joanne, or out on the golf course playing 18 holes, was age-related ... or from lymphoma. I still had had no treatment and felt like one of the luckiest guys in the world. Then two years ago I learned that the specific kind of lymphoma I had was something called Waldenstrom’s macroglobulinemia. I think my wife and adult daughters were always more worried about me than I was. My daughter Liz, a brilliant, successful entrepreneur in New York, started learning everything she could about Waldenstrom’s – first through reaching out to the Leukemia & Lymphoma Society and then to the IWMF.

“Early this year, trying to keep improving her growing understanding of my condition, Liz attended the New York Support Group’s April meeting – a month, as it turned out, before the Ed Forum. It was a very special support group meeting because it was more than just the typical and valuable group sharing. This one was a lecture from one of world’s leading Waldenstrom’s experts, Dr. Steven Treon, who’d been working for twenty years to conquer this orphan disease. Dr. Treon’s purpose that day was to bring patients and their families and caregivers up to speed on the great strides that were coming out of labs such as Dr. Treon’s at the Dana-Farber Cancer Institute. These strides reveal more and

The Elting Family, cont. on page 16

more understanding of the basic biology of Waldenstrom's – the precise cellular changes that turn an otherwise healthy person into a cancer patient.

"Liz was so excited and impressed by Steve Treon's presentation at this IWMF event that she called me that night, strongly suggesting that Joanne and I attend the IWMF Educational Forum in Phoenix the following month. Since it was not far from us in California, we signed up for the Ed Forum weekend, not knowing what to expect. Would it be a large group of sick, weepy people? Well, it turned out to be a fantastic experience – so much better and happier than I ever thought it could be, on three levels. First, Joanne and I met hundreds of upbeat, positive people. Seeing that was so encouraging. Second, I was also impressed by Carl Harrington and the IWMF Board – the whole organization. Everything at Ed Forum was done so nicely and so well. And third, we heard presentations by all of those terrific doctors who specialize in Waldenstrom's and dedicate significant parts of their careers to better treatments and, hopefully, a cure. It was a great weekend that really helped me see a better life even with Waldenstrom's."



A favorite Elting family photo of Ev and his daughter Liz.

MAKING A CHALLENGE GIFT TO SUPPORT HER DAD

With a strong desire to help others, Liz had always generously given back through philanthropy enabled by her entrepreneurial success. "Cancer runs in our family. My father was diagnosed with cancer years before he got Waldenstrom's – first at age 59. Also, heart disease is on my mother's side of the family, so I got quite involved with the American Heart Association, as well as with the Trinity College Board and the National Organization for Women. But cancer and heart disease are the truly big problems, and I can make a difference where it really counts.

"I told Dad over a year ago that I'd like to do something with lymphoma research. I wanted to get involved with a cause where I could have a major impact. When Dad was diagnosed

after the knee surgery, we were told he had a lymphoma– *but not which kind!* Only a couple of years ago did we learn that what he had was actually Waldenstrom's. That's when Dad reached out to the IWMF. He didn't have symptoms yet and, to tell the truth, if he hadn't been told he had cancer he'd never have known he was sick! We originally thought he had five years to live. But now we see that it's statistically a much better picture than that. I met so many great people at the April Support Group meeting, most impressively, of course, Dr. Treon, whose inspiring talk about the work he and the IWMF do gave us tremendous confidence and hope. I quickly came to feel that the IWMF was the right mechanism for me to become involved meaningfully with cancer and more specifically with my father's illness. Dad's great experience at the Phoenix Educational Forum only confirmed that feeling."

Working with the IWMF development team, Liz determined that her support should focus on the Strategic Research Roadmap Initiative that the IWMF has developed in partnership with the Leukemia & Lymphoma Society (LLS). As a result of the successful fundraising efforts in 2016, funds had been secured to support two to three new Roadmap projects and the IWMF Board was expected to approve financial support for those projects by the end of June. Liz saw an opportunity to make a real difference, challenging the IWMF to double its commitment to funding new research projects in 2017. She accomplished this by establishing the Elting Family Research Challenge, an offer to match research contributions to the IWMF, up to \$500,000. If commitments of \$500,000 could be obtained by July 1, the funds would be matched, dollar for dollar, enabling the IWMF to increase its funding commitment by \$1,000,000.

Setting up a major challenge grant program that needed to be completed in six weeks was itself a challenge. There simply was not enough time to organize a broad-based marketing campaign that would reach all of the members. However, in recent years several members had indicated that, if there were a special project that needed funding, they would be willing to consider helping. A plan was quickly developed to reach out to this relatively small group. Many of these donors were motivated by the prospect of enabling the Board to make additional research commitments as soon as possible. Accordingly, the response was overwhelmingly positive and the necessary commitments were secured by late June.

With the generosity of the Elting family and those who met the challenge, the IWMF Board was able to award five new research grants. This funding speaks loudly and clearly to both the research community and our members: the IWMF is committed to developing enhanced treatments, continuing to search for a cure. By funding eight new projects through the 2015 and 2016 Request for Proposals (RFP) processes, the WM community not only gets the benefits of the research that will be conducted, but also it signals to the research community that substantial funding for WM research is

The Elting Family, cont. on page 17

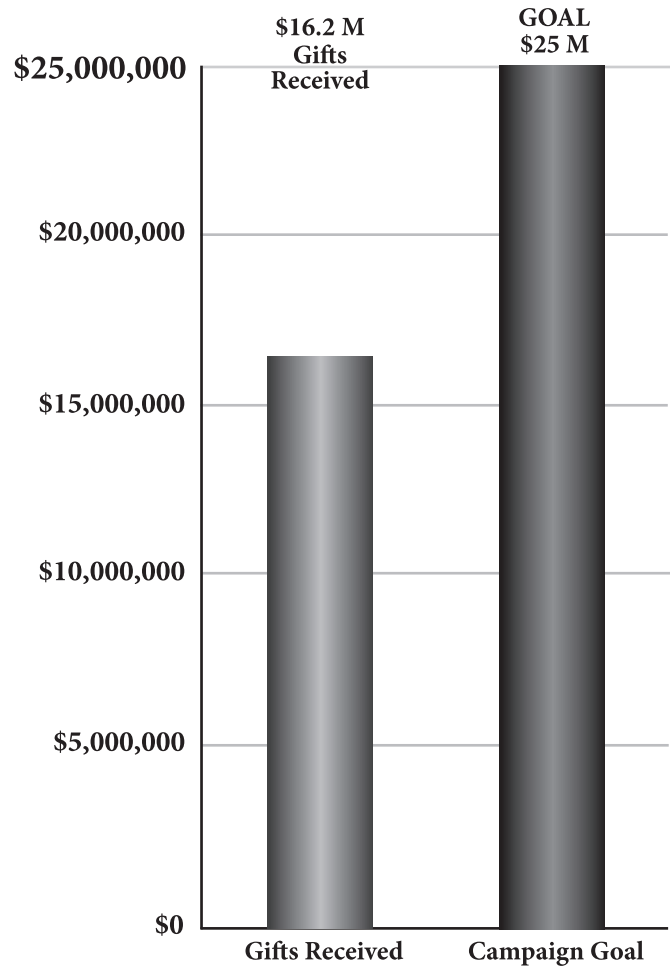
available. This will encourage more prominent researchers to focus on WM, increasing the number of proposals in the future.

The IWMF plans to issue another RFP in late 2017, with the initial target of funding two new projects next year. However, the number of proposals funded in 2018 will depend on the continued generosity of our members.

CLOSING THOUGHTS FROM THE ELTINGS

Ev Elting wakes up every morning to a life filled to the brim with optimism and energy. “Waldenstrom’s was nothing I ever wanted, but here I am, lucky enough to enjoy as much as ever, and maybe even a little more. I must say that our experience with the IWMF has been so positive for me, as I am so proud of my daughter’s initiative in learning more about WM, reaching out to the Foundation and her significant financial commitment to help me and others with my disease.” Liz concluded with uplifting words: “Our family has started a journey because of my father’s Waldenstrom’s. I wish we hadn’t, of course – for my father most of all – but as with so many others who have to deal with this disease, we are also reminded that adversity is a part of life, and it’s how we react to it and move forward that is important. Getting connected with the IWMF has meant a lot to us, and we are especially gratified to have had a way right off the bat to employ our financial resources to contribute to and generate such a strong member response in support of the IWMF’s research mission. Personally, I wanted to support my dad in a very direct way, as well as others with WM. The Elting family is thrilled to have joined with the IWMF team to advance our progress towards finding a cure.”

Imagine a Cure Campaign Progress Report as of July 31, 2017



IWMF DOC STAR: ZACHARY HUNTER

EDITED BY RON TERNOWAY



Zachary Hunter, PhD.

HIPAA... Umbrella... Imbruvica! How on earth do those dots connect?

The year is 2003 at the Dana-Farber Cancer Institute (DFCI) in Boston. Zachary Hunter, recently graduated with a BA in Mathematics from Haverford College in suburban Philadelphia, is working at a temporary position at DFCI while he maps out his future educational plans. His job is to explain to patients in

the waiting room the workings of the recently-enacted Health Insurance Portability and Accountability Act (HIPAA).

One rare rainy day in Boston, after speaking about HIPAA with Zach, a cancer patient left his umbrella in the waiting room when he went in to see his doctor. Hunter spotted the oversight, and when the patient exited the treatment area, Zach greeted him with his forgotten bumbershoot.

Impressed with Hunter’s manner and this act of kindness, the patient retraced his steps to the treatment room, and said, “Doctor, there is a lovely young man working here I think you should meet.” The doctor was Steven Treon. And meet they did.

IWMF Doc Star, cont. on page 18

Hunter accepted a one-year position to work with Treon to explore the mechanisms and evaluate treatments for Waldenström's macroglobulinemia (WM). It was a shoestring operation, with Treon, Hunter, and Andrew Branagan working mostly evenings and weekends in borrowed laboratories to further their research and to develop clinical trials for WM patients.

In 2005 the DFCI WM program was officially designated as the Bing Center for WM, in honor of Peter S. Bing, MD. Fast forward to 2017, where the Bing Center now numbers over 20 clinicians and researchers and cares for some 1000 WM patients worldwide, including 300 – 400 new patients annually.

In these dozen years, Hunter has been involved in multiple organizational and research projects, at the same time completing his PhD in Pathology at Boston University. He is also an instructor of medicine at Harvard Medical School. From familial WM to iron-deficiency to hypoglobulinemia to retinopathy, Dr. Hunter has had a hand in advancing the frontiers of knowledge about our shared malady. Website ResearchGate.net lists more than 125 scientific publications in which Hunter is credited as an author.

Hunter considers his most significant discovery to date to be the MYD88 genetic mutation present in 90-95% of WM patients, together with the subsequent exploitation of BTK-inhibitor Imbruvica to target this mutation. In 2016 Dr. Hunter received the Robert A. Kyle Award at the ninth International Workshop for Waldenström's Macroglobulinemia in Amsterdam for his groundbreaking research into CXCR4 and MYD88, which has led to improvements in diagnostic, prognostic, and therapeutic initiatives for WM.

Hunter is a gifted speaker, as anyone who has basked in his cadence, clarity, and brilliant slides at an Ed Forum can attest. His Genomics 101 talk in Phoenix was classic Hunter at his best. He has an extraordinary ability to explain difficult concepts in clear and simple ways, a skill he honed as a mathematics tutor during his pre-Dana-Farber days.

Ask Dr. Hunter what his most precious creation might be, and he smiles and brings out the photos of his 18-month old daughter, Soraya. He met his future wife, Noor Johnson, while at Haverford, then reconnected with her some years later. They have been married 3 years. Dr. Johnson earned her PhD at McGill University in Montreal and has done extensive fieldwork in the Canadian arctic, fostering Inuit involvement in climate change policy.

As for favorite activities when he takes off the white coat, Dr. Hunter cites cooking, baking, and hiking. He spent the first seven years of his life in rural Washington State and regularly returns to commune with the mountains and rainforest there.

As someone who has watched Dr. Hunter's progression as a researcher over the past 10+ years, our own Dr. Guy Sherwood, long-time IWMF Trustee and Vice-President for Research, is very enthusiastic about this young researcher. "I have had the pleasure of knowing Zach from near the very beginning of his career at the Bing Center for WM, and it has been a delight to watch him develop, both as a researcher and as a speaker at IWMF Ed Forums." Guy adds that "Zach is such a pleasant and genuine fellow and such a dedicated scientist – he is exactly the prototype of young talent we in the IWMF wish to nurture."

COOKS' HAPPY HOUR

BY PENNI WISNER

CONVENIENCE FOODS MADE AT HOME

Nope, not talking about opening cans, although I am not averse to or above that. I am talking about taking advantage of what is in season, cooking it, and then freezing it: in particular, eggplant. Maybe you step out to the grill without fuss or bother. Not me. So much inertia builds up against making a single extra step or making an effort when the results might not be appreciated (My sweetie does not care for eggplant, cooks it for me only under duress, and I have ceded the grill work to him.). Therefore, I look longingly at the fat, shiny, purple-black fruits and then pass them by. Not this year.

This year I will choose the fattest ones I can find, light the grill, and roast those babies whole over a very slow fire, turning them occasionally, until they are fully cooked. I invite

you to join me. The fruits when cooked will have turned black and the flesh will be very soft. As they are done, pluck them off the heat and pile them in a big bowl, cover it, and let them sweat and cool enough that they can be handled.

At this point, peel off the skins or pull the flesh off the skins. It depends on whichever is easiest to do: slit the fruits open along their length and use whatever method works best. Now, here is what I've learned in the last year: do not puree the flesh! Instead, divide it among freezer containers, storing the flesh from each eggplant separately since most recipes start with the request for "one or two large eggplants." Label and freeze. You will have then done the bulk of the preparation for any number of eggplant recipes. And, having done these on the grill, they will be full of that enticing smoky aroma.

Cooks' Happy Hour, cont. on page 19

Eggplant may be successfully roasted indoors, too, either right on top of a gas burner (messy) or on an aluminum foil-lined baking sheet under a broiler. But the grill results in the smokiest, best flavor. You believe me, right? (Depending on the weather, eggplant cooking might be a case of do what I say, not what I do.)

Enough! Let's start cooking with that roasted eggplant! From a book I've mentioned before, *Orient Express* by Silvena Rowe, I've made the Aleppo-Style Cumin Scented Baba Ghanoush. (Whatever our politics, we can feel saddened by the destruction of this historic and beautiful city and make this dish in the city's honor.) Take the shredded flesh of one large eggplant, give it a rough chop, and pile the flesh in a strainer placed over a bowl. Press down lightly to remove excess liquid. (Taste the liquid. If bitter, toss it, if tasty, add it to soups and salad dressing.) Transfer the drained flesh to a mixing bowl and add 1 teaspoon ground cumin; a small, fresh hot pepper such as a serrano, seeded, deveined, and minced; a small finely chopped yellow or red onion; a small tomato (preferably from the farmer's market; they should be with us until the first frost.), peeled, and finely chopped; 2 small garlic cloves, pressed; a small bunch flat-leaf parsley, finely chopped; the juice of ½ lemon, and the lemon zest, if you like; 2 tablespoons pomegranate molasses (a fancy name for unsweetened pomegranate juice boiled down to a syrup consistency. Pomegranates are also in season in the fall and if you have a tree, you are truly wealthy! Squeeze some and freeze the juice: another convenience food.); and a big glug of fruity olive oil. Mash together with a fork and season to taste with salt and pepper. Adjust the lemon and add more cumin if needed. Garnish, if you like, with roughly chopped walnuts (also a fall season crop!). Serve at room temperature.

My favorite cookbook, about which I have raved in this column, *The Jerusalem Cookbook* by Yotam Ottolenghi and Sam Tamimi, has another version of baba ghanoush they call Burnt Eggplant with Garlic, Lemon, and Pomegranate Seeds. Start with the flesh of one or more of your eggplants and drain it as above. Place the flesh in a bowl (Chop it or not, it's up to you.), and add a finely chopped garlic clove, the zest of a small lemon and a good squeeze of juice, about a tablespoon each of chopped parsley and mint, a glug of good olive oil, and salt and pepper to taste. Mix it all up with a fork and taste for seasoning. Pile the salad in a bowl and sprinkle with fresh pomegranate seeds. If you don't have them (But they should be available, very conveniently, in little plastic tubs in

grocery stores including Trader Joe's.), drizzle the salad with pomegranate molasses. If you prefer a stronger herbal flavor, add more fresh herbs or some za'atar (a Middle Eastern spice and herb blend).

A nice version might add finely chopped preserved lemon to the eggplant mixed with garlic and fresh or dried herbs of nearly any sort. (I no doubt thought of this as I sorted through the pantry and came across a jar of preserved lemons from a previous season – more convenience!) I think I would drizzle this eggplant salad with a tahini sauce (tahini, fresh lemon juice, pressed garlic, salt, and water).

Which brings me to my next enthusiasm. And question: Have you ever comparatively tasted tahinis? Now might be the time. While housesitting this summer, I discovered two brands of tahini in the refrigerator. One was leaps and bounds better than the other: sweeter, nuttier. But the ingredients of both were just the same. When I made hummus at her house and used the better tahini, the resulting hummus was irresistible. When home, I tasted the two I had: one purchased in bulk and a brand, Soom, sent as a gift. The former tasted slightly bitter while the Soom was sweet, nutty, full, aromatic. I was amazed. Does it have to do with care taken during toasting? The selection of sesame seeds? I have no idea, but I encourage you to buy higher quality tahini. Amazon carries the Soom brand as well as several Israeli brands including Tehina Al Erez and Al Arz. They are more expensive, yes, but these are so good, you may well find yourself pouring them onto your morning toast.

The tahini rant was not entirely a sidetrack. Next time you make hummus (and it is sooo much better than the best store-bought), use your high-quality tahini and this time puree the flesh of one of your roasted eggplant and stir it in. Heaven!

Allow me just one more side note: Have you noticed the packages of dehydrated and seasoned vegetables showing up in the snack food racks? I recently found "Just Beets" at Trader Joe's. The ingredients: Beets which are cooked, sliced, dehydrated. Not even any salt! The resulting chips are deeply colored, crisp, and utterly delicious. Serve them with your roasted eggplant salads. Or, since beets are also in season, cook, slice, and dehydrate your own!

Now, would you share with me your favorite convenience foods?

Our motto: Eat Well to Stay Well

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE



The 142 attendees at the Doctor-Patient Summit filled the auditorium of St. Catherine's College

UNITED KINGDOM

Since our July report, things have become very hectic. Our Doctor-Patient Summit at St. Catherine's College Oxford in July took a great deal of organizing and was a huge success with 142 attendees and a doctor-patient dinner the night before in College Hall. The ten doctor and clinical nurse specialist team led by WMUK trustee Dr. Jam Kothari not only delivered great presentations but made themselves available for one to one talks throughout. Patients particularly appreciated Dr. Iain Jordan of Oxford University Hospital on the psychological effects of living with a chronic malignancy – a new area for us. In conjunction with the Lymphoma Association, we offered our first breakout session for the increasing number of younger diagnosed where we showed our first patient tale video (now on our website, www.wmuk.org.uk).



On the night before the WMUK Doctor-Patient Summit at St. Catherine's College Oxford in July, doctors and patients dined in College Hall.

A highlight was the presentation of the first Rory Morrison Clinical Award to Dr. Shirley D'Sa of London's University College Hospital (UCLH) for her tireless work in improving patient treatment. We were able to announce the formation of a national patient focus group based at UCLH to share and study the effects of living with WM with a view to publication of results.



As part of the campaign to secure approval with the Cancer Drugs Fund for ibrutinib for relapsed patients, Dr. Joshua Bomsztyk has been appointed as project manager to run a detailed data collection scheme using WMUK's Rory Morrison Registry through 12 major UK hospitals.

Previous reports outlined the convoluted two-year campaign for ibrutinib for relapsed patients with the Cancer Drugs Fund (CDF). All involved, including Janssen UK, have been forced to jump over bizarre hurdles, seemingly designed to slow down adoption. Janssen showed a huge commitment to the WM community in negotiations, which were being finalized as this is written. As part of the CDF process, Janssen agreed to fund a detailed data collection scheme using WMUK's Rory Morrison Registry through 12 major UK hospitals. Dr. Joshua Bomsztyk (pictured)

has been appointed as project manager to run it from UCLH. If extra resources can be found, then data collection will be rapidly extended to other centers throughout the UK. This is a great leap forward. It takes us into a new era and moves forward the development of WM centers of interest throughout the UK, pioneered by our Doctor Forum. Additional interest is being created by a patient-reported outcomes data layer in the Registry that can be filled via an app on mobile phones.

We were also able to work with BeiGene to roll out and publicize the opening of the BGB-3111 versus ibrutinib trial through eight sites in England and Wales; the first opened in Bournemouth in July. Hopefully this will address the relative lack of UK trials for novel treatments. Encouraging these trials is vital, as the UK's drugs regulator seems to attach more weight to UK results.

Roger Brown, WMUK, reporting from deepest Epping Forest.

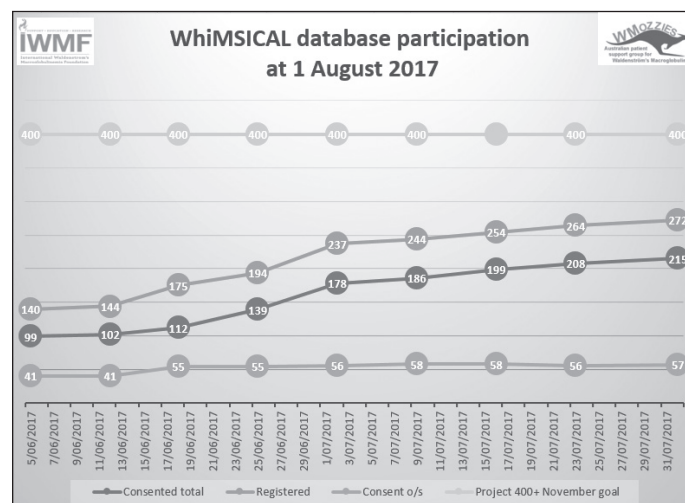
AUSTRALIA

WMozzies member joins the Ben Rude Heritage Society

WMozzies member **Peter Carr** was recognized as a new member of the Ben Rude Heritage Society at the IWMF Educational Forum held May 19-21 in Phoenix, AZ. Established in memory of Ben Rude, second president of the IWMF, the Society honors those who have made legacy gifts to the IWMF. See the photograph on page 20 of the *July Torch* (issue 18.3 2017) where Peter and other new members are thanked by Laurie Rude.

WhiMSICAL database

An abstract on the WhiMSICAL database has been submitted to the 2017 American Society of Hematology (ASH) Annual Meeting. The ASH meeting is the premier and most significant hematology conference worldwide with over 10,000 hematologists attending. The abstract on the WhiMSICAL database presents unique and informative progress data analysis results from the WM medical data submitted by WM patients globally. Patients from eleven countries have contributed including US 45%, Australia 26%, Canada 10%, UK 8%, and NZ 5%. Data from over 200 WM patients was included in the July submission. Updated data with a planned doubled participant goal are to be submitted before the December ASH meeting. All WM patients are encouraged to join or update their details in the WhiMSICAL database before then.



Blood Buddies support program

WMozzies are working with the Leukaemia Foundation in their Blood Buddies Australia wide peer support program. The Blood Buddies Program provides short-term support on a one-on-one basis to people diagnosed with blood cancer or to those caring for one. This is done by connecting them with people who have survived similar diseases, treatments, or situations. For many people, coping with a difficult life experience is made a little easier by talking with someone who has been through a similar experience before. WMozzies volunteers undertake specific training through the Leukaemia Foundation's formal program. People referred to this program are matched, on a number of key indicators, with a trained volunteer, known as a "Buddy." The Foundation provides Blood Buddies volunteers with training and ongoing support to ensure their physical and emotional wellbeing while engaged in the program. It also provides Blood Buddies one-on-one support to people with many different types of blood cancers and related diseases.

Andrew Warden, WMOZZIES, reporting.

INDIA AND MEXICO

The IWMF very recently announced the establishment of two new International Affiliates, Waldenstrom India (WM-India) and Waldenstrom Mexico (WM-Mexico).

WM-India will be located in Bangalore and will focus its WM support efforts to patients and caregivers in three large cities: Mumbai, Bangalore, and Kolkata.

WM-Mexico will support WM patients in Mexico City.

The *Torch* extends a very warm welcome to Saurabh Seroo, Support Group Leader of WM-India, and to Leopoldo (Polo) Peña, Support Group Leader of WM-Mexico.

We look forward to hearing from you and sharing your news with the rest of the IWMF world!

EUROPEAN HEMATOLOGY ASSOCIATION MEETING IN MADRID

SESSION ON WM HEAVILY ATTENDED



The auditorium at the European Hematology Association Meeting was packed to hear Dr. Treon and Dr. Stathis Kastritis speak on recent results of genetic studies of and treatments for Waldenstrom's macroglobulinemia.



Dr. Steven Treon speaking at the European Hematology Association Meeting held this past June in Madrid.

of Salamanca, Spain, chaired the session.

Dr. Treon discussed the importance of the MYD88 and CXCR4 mutations in WM that are present in 90-95% and 30-40% of WM patients, respectively. Both mutations were discovered in the Treon laboratory following whole genome sequencing. Dr. Treon elaborated on the cell signaling that occurs by the MYD88 and CXCR4 mutations and on efforts to target these mutations by new treatments.

The 22nd European Hematology Association (EHA) meeting was held in Madrid, Spain, and featured an Educational Session focused on Waldenstrom's macroglobulinemia (WM). Over 1,000 attendees, mainly clinicians, packed Hall C at the EHA meeting on June 25, 2017, for the session that featured presentations from Dr. Steven Treon, Harvard Medical School, Boston, USA, and Dr. Stathis Kastritis, University of Athens, Greece. Dr. Maria V. Mateos of the University

Dr. Treon further discussed the importance of ibrutinib (Imbruvica) in targeting MYD88 signaling and the recent approval of ibrutinib by the US Food & Drug Administration and European Medicines Agency for the treatment of WM. He also discussed efforts in the Bing Center Laboratory, Dana-Farber Cancer Institute, Boston, to develop new drugs that target MYD88 signaling, including inhibitors of the IRAK and HCK pathways. Dr. Treon also discussed new clinical trials made possible by genomic advances, including a study of ulocuplomab (BMS-936564) that targets CXCR4, a protein whose role in drug resistance was first reported by his laboratory. In addition, Dr. Treon also discussed a trial that targets BCL2 using venetoclax (ABT-199) and its potential use in combination with ibrutinib.

Dr. Stathis Kastritis presented new data from clinical trials, including two studies focusing on the role of ibrutinib in previously treated WM patients. Dr. Kastritis reported an overall response rate of 90% in both studies, with durable responses. Dr. Kastritis discussed the use of ibrutinib in the context of current treatment options that include rituximab, alkylator drugs (cyclophosphamide and bendamustine), and proteasome inhibitors (bortezomib and carfilzomib).

An interview by Dr. Treon at the European Hematology Association on progress in WM made possible by genomic advances can be found at:

<http://www.vjhemonc.com/video/uwkezdnpicw-eha17-steven-treon-vjho-02/>

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER



Attendees at the ninth annual Chicago Area picnic enjoyed "beer-simmered brats, great fellowship, and unusually nice Chicago weather."

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

The next SoCal meeting is scheduled for November 12 when the group will welcome Dr. Steven Treon to City of Hope. Please refer to iwmf.com under EVENTS to confirm details.

COLORADO AND WYOMING

New patients with a need to talk got their opportunity to share and learn from support group members with 15 to 20 years' experience at the summer meeting, which took place at the University Park United Methodist Church, a convenient and central location. Attendees got reacquainted, or introduced themselves for the first time, over a potluck breakfast. Of the twenty-two who came, six were new to the group, several recently diagnosed, and others who had just moved to the area. A lively discussion started with the new folks: to hear their issues, questions, and to provide encouragement. Practical tutorials were included such as navigating the IWMF website in order to view presentations from the IWMF Educational Forums. Particularly helpful to all patients attending was the opportunity to compare suggested treatment options with people who have actual experience with those same treatments. Everyone left the meeting both more confident and hopeful and grateful, too, for the health care providers with WM experience who are available locally. Dr. Jorge Castillo from DFCI will be in Denver on October 14 to meet



Four of our new members: Alan Doksansky (Dx 2016); John White (just relocated here from PA, Dx 1996); Pat Leonard (Dx 2014); Cathy Curtin Cleary (Dx 2016).

with the group. Please refer to iwmf.com under EVENTS to confirm details.

CONNECTICUT

In June, a record-setting number of attendees listened as Dr. Madhav Dhodapkar of the Yale University School of



The CT WM Support Group had a very profitable session with guest speaker Dr. Madhav Dhodapkar, recipient of an IWMF-LLS Roadmap grant.

Support Group News, cont. on page 24



Don Brown and Sara Thran played another round of their ongoing ping pong competition.

Medicine gave an intimate look at the work being done by his medical research group. The IWmf and LLS sponsor his research project, “Origins of Immunotherapy of WM,” as part of the Strategic Research Roadmap. Our biannual meeting took place at Yale-New Haven Hospital in New Haven. Dr. Dhodapkar followed his presentation by leading a question and answer session. Before adjourning, there was an opportunity for individuals to share their WM journeys. The sharing was informative and beneficial to everyone there. The next meeting is scheduled for October 14 in Farmington, CT, at Westfarms Mall. Please refer to iwmf.com under EVENTS to confirm details.

ILLINOIS

Chicago Area/SE Wisconsin

On the first weekend in August, **Mike and Sara Thran** hosted the group’s ninth annual picnic at their home in Elgin, Illinois. One member drove to the picnic in his 1904 Oldsmobile (see page 29) which he had restored himself. The picnic was a great success with beer-simmered brats, great fellowship, and unusually nice Chicago weather. Special thanks to Sara for offering her home for the fifth time in the last nine years. The picnic ended with the usual friendly ping pong competition between Sara and Don. The next and final meeting of 2017 will be held on October 21. Dr. Sherine Elswa, Associate Professor at Northern Illinois University, who received an IWmf research grant for her work on Waldenstrom’s, will be the guest speaker. Please refer to iwmf.com under EVENTS to confirm details.

MINNESOTA & WESTERN WISCONSIN

Heidi and Scott Vlasak graciously hosted the group’s annual picnic at their home on a great weather day. Nineteen members enjoyed a healthy variety of dishes shared by all. Discussion topics included gleanings from the May IWmf Educational Forum (and the first annual fund-raising 5K walk that took place at the event). Newer members were thankful for the opportunity to share their experiences and hear from the

more experienced attendees. They were encouraged to meet some WMers who had been diagnosed over seventeen years ago. The next meeting will be a member panel discussion on October 7. Please refer to iwmf.com under EVENTS to confirm details.

NEW ENGLAND

Boston

On a Sunday afternoon in mid March, after two postponements due to snowy weather, the group finally met at DFCI in Boston. **Chris Patterson** from the Bing Center for Waldenstrom’s Macroglobulinemia acted as host. In addition to reconnecting with each other and welcoming new members, the group was fortunate to have a guest presentation from Toni Dubeau, Nurse Practitioner for the Bing Center: “Self Care: Exercise, Diets, Supplements, and Fatigue.” Toni has been working with cancer patients for over 30 years and had some great suggestions.

NEW YORK

Rochester, Western, and Central NY

In May, the group met for lunch at Gilda’s Club, a Rochester community center which offers services to men, women, teens, and children affected by cancer. Dr. Carla Casulo from the University of Rochester Wilmot Cancer Center was the guest speaker. She covered the basics of WM, diagnosis, and treatment, including a discussion of current and promising future treatments that employ the patient’s own immune system. The presentation was clear and understandable. It was evident that Dr. Casulo is dedicated to her patients and to research. Everyone was extremely appreciative to Dr. Casulo for attending the meeting and providing such an informative talk that left the members feeling hopeful and enlightened. The group plans to meet in September for lunch and to catch up with one another. Please refer to iwmf.com under EVENTS to confirm details.

PENNSYLVANIA

Philadelphia

Have you heard about “Mindfulness”? Ever wondered what all the hype is about mindfulness meditation and whether it really works? This summer, the Philadelphia group hosted Gabriel Rocco, a renowned meditation teacher with over 25 years’ experience teaching meditation techniques to cancer patients (details about Mr. Rocco are below). During the ninety-minute session, Gabriel presented a series of short meditations on breathing, body, and mind to release unnecessary physical tensions, destructive emotions, and thoughts common to people living with cancer. These contemplative practices supported a gentle and caring acknowledgment of distress as a path to finding one’s inherent strength and an ability to respond in healing ways to the challenges one meets in everyday life. No prior experience was necessary. It was a friendly and low-key introduction to mindfulness meditation techniques. Some attendees had long-standing meditation practices and some were absolute beginners, but everyone enjoyed and benefited immensely. The best part of all: some members admitted afterwards that they had been extremely skeptical of learning about meditation and came to the meeting reluctantly but then were delighted and surprised at how much they learned and enjoyed themselves! Here is one testimonial: “Gabriel was great! With many decades behind me, meditation was never something I ever considered, since I am a pretty peaceful and happy person. Yesterday was the first time I “got it.” It was quite pleasant and I was shocked that I thought so. I am always so eager attend the meetings, but wasn’t excited about “meditation and mindfulness.” I never mind admitting I am wrong. Thank you for inviting him!” Gabriel Rocco teaches meditation and mindfulness-based stress management to individuals and groups, and he supports people living with cancer or other serious illnesses to integrate a variety of mind body methods into their healing journey. Gabriel teaches at the University of Pennsylvania’s Program for Mindfulness and Contemplative Arts in Bryn Mawr, PA.

TEXAS

North Texas

The group met in June at the Baylor Sammons Cancer Center in Dallas to hear a presentation by Dr. Jorge Castillo from the Dana-Farber Cancer Institute. Dr. Castillo gave some background on WM but focused much of what he said on the issues related to the MYD88 and CXCR4 mutations. He also discussed current treatments from Rituxan to ibrutinib as well as drugs, such as venetoclax, which are being used in some clinical trials. He cautioned that each patient is an individual and that treatments should be based on an individual’s symptoms and not just test results. Those



Members of the North Texas Support Group pay close attention as Dr. Jorge Castillo reviews the many new directions of WM research and treatment options now available.

listening were impressed to learn all the treatment options that have been developed within the past few years and were also excited by the expectation that the coming years will be even more fruitful as research discovers new treatments. After his presentation, Dr. Castillo joined the members for a brunch generously provided by the Baylor Sammons Cancer Center. During the meal, Dr. Castillo made further remarks about WM and answered some questions for individuals. After Dr. Castillo left, the members had a share time. The group is so grateful to Dr. Castillo for sharing his expertise and for his willingness to visit with us informally.

Houston

No one needed to get on an airplane mid-August to attend Dr. Zachary Hunter’s appearance at the Houston support group. Instead, Dr. Hunter, researcher at the Dana-Farber Cancer Institute, beamed in from Boston via WebEx to present his lecture “Updates on the Genomic Research in Waldenström’s Macroglobulinemia.” The attendees were pleased to learn about WM advances and upcoming, new treatment protocols. After the lecture, Dr. Hunter graciously answered many of the group’s questions. After Dr. Hunter signed off, the group settled down to enjoy a pot luck dinner at the home of **Dr. Barbara** and **John Manousso**.

WASHINGTON

In August, seventeen group members gathered to hear a very useful presentation by clinical psychologist Samantha Artherholt Burns on stress management. Her slides listed helpful suggestions for recognizing the difference between the situations an individual can and cannot control and the two coping techniques of dealing with them: problem-focused and emotion-focused. It led to good questions and discussion – and lots of people happy to learn that dark chocolate can help relieve stress.

Because ibrutinib can temporarily lower the number of white cells in the blood, the patient is at greater risk of getting an infection. This also means that if there is an infection brewing in a tooth (root canal), bone, or gums (periodontal), it may well go from a quiescent state (subclinical) to a full-blown infection with internal or external swelling due to the drug's side effects or the patient's immunosuppression (low IgG). Ibrutinib can also lower the number of platelets (thrombocytopenia) and may prevent proper blood clotting.

If you are having a tooth removed, implant placed, gum (periodontal) surgery, or other surgical procedures, inform your dental and medical team. They may recommend that ibrutinib be discontinued for 3-7 days pre- and post-surgery, depending on the risk of bleeding. Generally, surgical procedures should not be done if the platelet count is below 50,000.

Acquired von Willebrand disease is a bleeding disorder that may occur with high IgM level. Testing for von Willebrand activity is recommended in WM patients with a history of bleeding prior to starting ibrutinib therapy. Patients with von Willebrand disease may require pre-treatment with medications, such as desmopressin, prior to dental treatment that carries high bleeding potential.

See below for mouth sores associated with ibrutinib.

Oral Bleeds, Mouth Sores, Change in Taste, Dry Mouth, Nausea, Vomiting

Although rarely serious, **oral bleeds** can be of concern to the patient and family. Oral bleeding may be mild (e.g., small red spots (petechiae) located on the lips, posterior palate, or floor of the mouth) or severe (e.g., persistent gum (gingival) hemorrhage or bleeding from herpes simplex virus ulcers) if the patient has very low platelet counts (thrombocytopenia).

Mouth sores (mucositis, esophagitis) can range in severity from a red, sore mouth and gums to very painful open sores, causing a patient to be unable to eat normally. Normal oral mucosa (the inside lining of your lips and cheeks) is estimated to undergo a complete replacement every 9-16 days.

Ibrutinib can cause ulcerative mucositis that emerges approximately 7-10 days after initiation of the drug. The mucosa that lines the inside of the lips and cheeks, the tongue, floor of the mouth, and soft palate (the part of the palate that is back towards the throat) are more affected than the gums and front part of the palate. Methotrexate also has a high propensity to damage the mucosa and create mouth sores. Most medical teams will prescribe oral corticosteroids, such as dexamethasone, for their anti-inflammatory properties. By reducing the body's natural defensive response, dexamethasone reduces swelling and irritation from the mouth sores.

There is some evidence that using 3% hydrogen peroxide rinses diluted 1:1 with water to remove the dried blood associated with the mouth sores may be helpful; however, this approach

should only be used for 1-2 days because more extended use may impair timely healing of the mucosal lesions associated with the bleeding. Keeping well hydrated and eating ice chips and ice water prior to meals can alleviate some of the pain while eating. Try to avoid mouth rinses with alcohol, as these can make the mouth sores even more painful. Mouth sores heal on their own in 2-4 weeks after stopping the drug when uncomplicated by infection. Continuing to perform good oral hygiene can speed the recovery along. There is anecdotal evidence that suggests that patients who experience mucositis with a specific medication during the first cycle will develop comparable mucositis during subsequent courses of that regimen.

Patients sometimes complain of a **metallic taste or other taste changes** during treatment. Sometimes these can be due to a nutritional problem and referral to a nutritionist may be appropriate, but in the interim, overpowering the metallic taste may help. Sugar free lemon drops or mints or chewing strongly flavored sugar free gum may provide relief. Adding extra flavoring to food, such as marinades, herbs, vinegar, or pickled vegetables may overpower the metallic taste, as well.

Dry mouth (xerostomia) is another side effect of ibrutinib and other chemotherapeutic drugs that is often transient and can be treated. Plasma cells in the salivary glands of the mouth produce IgA for the saliva, and IgG is contributed to the saliva from the serum. The IgA binds to the inner lining of the mouth (mucosa) to form a protective layer that may be lost, contributing to mouth sores and dry mouth symptoms. Hyposalivation (reduction in saliva) can further aggravate the inflamed mouth sores, increasing the risk of infection and make eating and swallowing difficult. There can also be thickening of the saliva due to changes in the salivary glands themselves. For relief, sip water, as needed, to alleviate mouth dryness. Saliva substitutes or artificial saliva preparations (e.g., oral rinses or gels containing hydroxyethylcellulose, hydroxypropylcellulose, carboxymethylcellulose, polyglycerylmethacrylate, mucin, or xanthan gum) may relieve the discomfort of xerostomia by temporarily wetting the oral mucosa. Rinsing with a solution of 1/2 teaspoon baking soda (and/or 1/4 or 1/2 teaspoon of table salt) in 1 cup of warm water several times a day helps clean and lubricate the oral tissues. Chewing sugar free gum or sucking on sugar free lozenges helps to stimulate salivary flow.

Nausea and vomiting over a prolonged period of time can etch and eventually wear away the enamel of teeth making them exquisitely sensitive to cold and putting them at risk for decay. The medical team can prescribe anti-nausea (antiemetic) medications to help manage the queasiness. Avoiding triggers, such as heavy or greasy or fatty foods, spicy or acidic foods (lemons, tomatoes, and oranges) may help. Antacids (milk of magnesia, calcium tablets, Tums), saltine crackers, or sugar free ginger ale may also lessen

the nausea. Sodium bicarbonate toothpastes and rinses help counter the acidity produced with vomiting.

Dental Management during Therapy for Patients with WM

Routine oral hygiene is important for reducing the incidence and severity of oral and dental problems. The National Cancer Institute recommends tooth brushing 2-3 times a day with a soft nylon bristled brush, rinsing frequently. More frequent brushing may be necessary to remove food and plaque if xerostomia (dry mouth) is present and there is reduced salivary flow. Using a fluoridated toothpaste is recommended, especially if the patient lives in a non-fluoridated community. Using non-mint flavored toothpaste may be better tolerated than mint flavored products when a mucositis is present. Rinsing the toothbrush in hot water every 15-30 seconds during brushing will soften the bristles and reduce the risk for trauma. Brushes should be air-dried between uses. Ultrasonic brushes may be substituted for manual brushes if the patient has been trained by the dental team in their use.

For younger patients with aggressive WM for whom other treatments are no longer working, allogenic (donor generated) stem cell transplantation may be an option as part of a clinical trial, if the patient's own stem cells (autologous) are not available. Although not commonly used for WM, allogenic stem cell transplantation produces patients who are at increased risk for graft-versus-host disease (GVHD). This condition, where the patient's immune system is taken over by that of the donor, may have severe oral manifestations. The use of non-mint flavored toothpaste may be better tolerated, as these patients are most at risk for severe mouth sores.

If possible, floss once a day before bed. Avoid rinses containing alcohol. Poorly fitting dentures or other appliances should not be worn during times of low platelet counts, if bleeding is a problem. Leave dentures and other appliances out of the mouth when sleeping and during periods of severe mouth sores. Prevent dryness of the lips from mouth breathing or dry mouth with lanolin-based creams and ointments (lanolin-based products are more moisturizing and lubricating than petroleum-based oils and waxes).

Dental brushing and flossing represent simple, cost-effective approaches to bacterial dental plaque control. This strategy is designed to reduce risk of oral soft tissue infection during therapy. Spontaneous gum (gingival) oozing may occur when platelet counts drop below 20,000, especially when there is preexisting gum inflammation (gingivitis) or gum and bone disease (periodontitis). Even normal function or routine oral hygiene (brushing and flossing) can induce gum oozing in the face of preexisting gingivitis and periodontitis. Oncology teams at some centers promote their use, while teams at other centers have patients discontinue brushing and flossing when peripheral blood components decrease below defined thresholds (e.g., platelets < 30,000). There is no comprehensive evidence regarding the optimal approach. Many centers adopt the strategy that the benefits of properly

performed dental brushing and flossing in reducing risk of oral/dental infection outweigh the risks.

Patients may experience temporomandibular dysfunction pain involving muscles used for chewing (mastication), temporomandibular joints, or teeth. This condition is not unique to WM or cancer patients per se, and it correlates with stress and dysfunctional habits including grinding the teeth (bruxism) and clenching of the jaws. Stress and sleep dysfunction appear to be the most frequent etiologic factors. Judicious use of muscle relaxants or anxiety-reducing agents plus physical therapy (moist heat applications, massage, and gentle stretching) is the standard approach for management. For patients with a tendency for clenching or grinding teeth during sleep, the use of customized, removable occlusal splint appliances that cover the teeth while sleeping may be of value.

Bisphosphonates

Although not specific to WM, we would be remiss if there were not a discussion of bisphosphonates. Bisphosphonates are a class of drugs that prevent bone loss. Patients should understand that although bisphosphonates are effective, these drugs also carry risk to their dental health. Bisphosphonate treatment can cause a rare but serious side effect called "osteonecrosis of the jaw (ONJ)." ONJ causes part of the jaw bone to die, which can lead to pain, open sores, and higher risk of tooth loss and infection. Patients should have a dental check-up before starting treatment with this class of drugs and address any dental problems before treatment begins. Doctors will stop the bisphosphonate treatment if ONJ occurs. The occurrence of ONJ is based on cases reported in the literature, and occurrence ranges from between 1% and 10% for patients receiving the intravenous formulation (pamidronate and zoledronic acid) to less than 1% for patients taking oral bisphosphonates. NCI's PDQ cancer information summary about bisphosphonates and ONJ states the risks succinctly: dental extractions, ill-fitting dentures, intravenous bisphosphonate, time on medication, and multiple myeloma. Some clinicians believe that discontinuing the drug for patients scheduled for dental surgical procedures may be beneficial, although this belief is not supported by scientific study. It is recommended that such a drug holiday be maintained until clinical evidence of healing is observed. However, controversy surrounds this issue, and further research is needed.

Conclusion

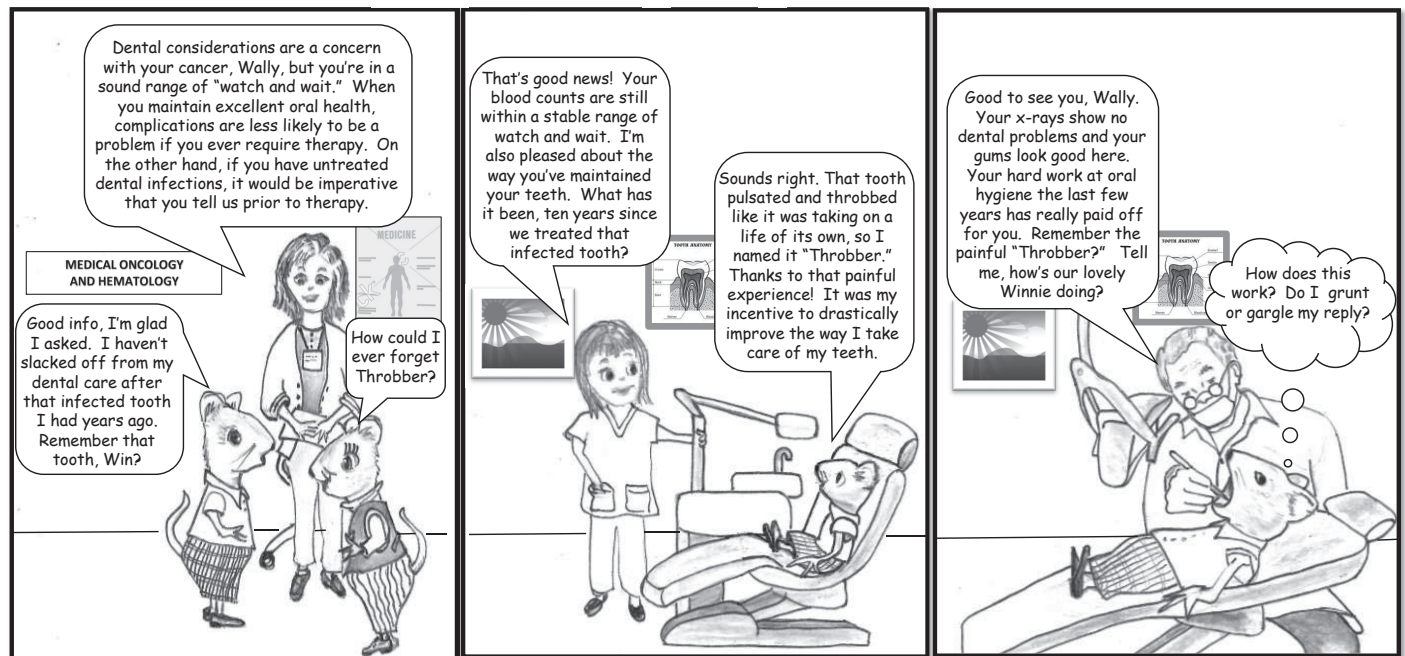
With any treatment for WM it is imperative that the patient tell the medical team about any dental infection (tooth, gum or bone) that the patient has before initiating therapy. Most of the drug therapies will lower the body's ability to fight infection. When asked about infections, many patients forget to report about their teeth, leading to management problems down the line. The oral cavity is highly susceptible to direct and indirect effects of drug therapies. This risk results from

multiple factors, including high rates of cellular turnover for the lining of the mouth, a diverse and complex microflora of bacteria, viruses, and fungi, and trauma to the oral tissues during normal oral function.

For Further Information:

PDQ® Supportive and Palliative Care Editorial Board. PDQ Oral Complications of Chemotherapy and Head/Neck Radiation. Bethesda, MD: National Cancer Institute. Updated. Available at: <http://www.cancer.gov/about-cancer/treatment/side-effects/mouth-throat/oral-complications-hp-pdq>. Accessed March 31, 2017. [PMID: 26389320]

WALLY AND WINNIE, WM Model Mice by Linda Pochmerski



Wally learned several years ago that straying away from his routine plan for oral hygiene compromised his dental health. The good news is he turned his pain into positive gain by achieving excellent oral hygiene thereafter. That painful "Throbber" is now just a memory.

We Get Letters!

The Torch received the following letter in response to the article "Profile of a Cryo Patient" by Fay L, published in the July issue (Volume 18.3) on pages 7-8.

The Torch,

Att: Officers, Trustees, Staff, and Volunteers

Re: page 8 Profile of a Cryo Patient: Fay L

Fay's Tips for AVOIDING infections:

This is the most valuable, informative, clear-cut guide ever produced. Every single cancer facility, every single MD's office, should have this available as a handout to provide their patients with a "daily code of survival" to AVOID INFECTION.

Unfortunately, I keep coming down with infections, and now Ms. Fay L has described to me the reasons why and how to prevent them.

Thank you and thanks to Fay L.

Sincerely,

Persia Tuvim

St. Augustine, FL

A PATIENT PATIENT: JOHN GEBHARD AND HIS 1904 OLDSMOBILE

BY DON BROWN, SUPPORT GROUP LEADER CHICAGO AREA



This Olds has a tiller instead of a steering wheel! John Gebhard at the tiller on the left and passenger Don Brown take a spin in John's restored 1904 Curved Dash Oldsmobile Runabout.

As Chicago Area support group leader Don Brown and wife Mary made the last turn into Sara and Mike Thran's house in Elgin, IL, to attend the group's ninth summer picnic, Don noticed a really old car merging onto the road. As the car followed Don into the driveway, he realized it was long-time member and WMer, John Gebhard. John backed into the grassy area near the driveway to avoid leaving an oil slick on the driveway. He had traveled for 45 minutes to cover about seven miles of side roads to avoid traffic. His topless, horseless carriage, a 1904 Curved Dash Oldsmobile Runabout, with its six horsepower, single-cylinder engine (less than many lawnmowers), can reach a top speed of only 25 miles per hour. The old Olds is a two seater with a tiller

instead of a steering wheel (see attached picture). John, who has restored and maintained several classic cars, shared his passion for old cars with his father who passed away in 1996.

Olds Motor Vehicle Co. was founded by Ransom E. Olds in 1897. John's model started production in 1901 and became the most common "horseless carriage" in the USA before being overtaken by the Model-T when it came into production in 1907. John is a patient patient as he tours the Midwest slowly in his Oldsmobile as well as a Model-T, which he recently added to his collection in order to be able to give his grandchildren rides. John treats his cars with a skilled engineer's hand and mind and enjoys touring in the back roads of the Midwest with the Horseless Carriage Club of America. When fellow club members take the "paved roads"

to avoid damaging stones, John takes the more direct gravel roads as he heads to unique destinations such as a farmer's WWII B-17 restoration project.

John has been "patiently" on "watch and wait" since 2002 and helps take care of his wife, Linda, who for two years has been battling stage four kidney cancer. There were quite a few science and engineering professionals at the annual picnic, all of whom enjoyed discussing John's classic car hobby. John is a retired video systems design consultant who has worked on projects from mega-churches to major sports venues. He trained in the Navy from 1966 to 1972.

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

Jane A. Attridge

Anonymous

Ann M. Cross

Mr. and Mrs. Nicolas DiCiaccio

Walter Dere

Laura Dere

Jann Edwards

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