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INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

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2018 ED FORUM: A LOOK BACK

Spring is that time of year when our thoughts turn to hope, renewal, and optimism—and in the case of many WMers, those thoughts lead to the annual IWMF Educational Forum. Indeed, this year a new attendance record was set at 373—60 more than last year's record!

The 2018 Educational Forum participants came with the hope of hearing about new treatments under development for this rare blood cancer. They also came with the expectation of renewing old friendships, making new friends, and learning how each of us is surviving the challenges of living with WM, a blood cancer that is almost always treatable and that one day (soon we hope) will be curable. This was also a time of optimism for WMers everywhere, as the Ed Forum theme, repeated over those three days, was *Imagine a Cure: Closer Than Ever*.

Popularly referred to as the “Ed Forum,” this year's event was held on May 18-20 at the Westin O'Hare Hotel in Rosemont, IL. WMers coming from all directions within the US (and from an impressive number of regions in the wider world as well) gathered for three intense days to follow a program packed with topics concerning WM.

Thursday, May 17, Getting Ready...

Thursday, the day before the official start of the Ed Forum, was a busy one. Support group and affiliate leaders from all over (including Australia, Canada, China, India, Mexico, and the United Kingdom!) met for lunch and a workshop to share their ideas for improving the IWMF support group experience. Meanwhile, the AV crew was outfitting the Grand Ballroom with sound, lighting, and screens, and the videographer was setting up his camera to record the general sessions throughout the weekend.

IWMF Meeting Coordinator Sara McKinnie, several IWMF office staff members (Jennifer Silva, Dave Benson, Jeremy Dictor, and Ashley Nguyen), and Sara's merry band of Ed Forum volunteers were active behind the scenes too...meeting with the hotel staff, getting the registration and exhibit tables ready, putting out literature and name badges, setting up research posters, and stuffing the black-and-white attendee tote bags with all kinds of information necessary to get the most from the Ed Forum. Volunteer photographer Tom Shyver was circulating to capture this activity, as he did throughout the Ed Forum. As the early bird registrants started coming in, they were greeted with friendly smiles and helping hands from the volunteers.

Friday, May 18, the Ed Forum Kicks Off!

Friday began early, with a special session called *The ABCs of WM*, geared toward the
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newly diagnosed or those who wanted a refresher course on WM. Dr. Jeffrey Matous of the Colorado Blood Cancer Institute ably started off this session as he has for the last two Ed Forum. Dr. Matous covered the basic science behind WM; how the disease is defined; the typical signs, symptoms, and potential complications of the disease; how to diagnose and monitor WM; the differences between IgM MGUS, smoldering WM, and active (symptomatic) WM; the concept of “watch and wait”; and when it is appropriate to begin treatment. This was an excellent way to begin the Ed Forum, laying the foundation for all the presentations to follow. Dr. Matous left plenty of time for questions, and there were many!

The second part of this session was led by Dr. Neil Massoth, a psychologist and long-time WM patient, former support group leader for New York City, and former IWMF Trustee. His focus was on *The Patient Perspective on Being Newly Diagnosed*, and he discussed how the diagnosis of WM can impact patients and caregivers. Probably the most common reaction that patients have is anxiety, not just from the diagnosis of cancer, but because WM is rare and most people have not heard of it and do not understand it. Dr. Massoth also discussed several coping mechanisms, such as becoming an educated and informed patient, reducing stressors, putting a support system in place, and surrounding yourself with life-affirming people.

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Waldenström's macroglobulinemia is coded 273.3 in the International Classification of Diseases (ICD) of the World Health Organization.

IWMF President Carl Harrington officially opened the Ed Forum at 11am, welcoming everyone and explaining what the Ed Forum was all about; he was followed by Dr. Shuo Ma of Northwestern University, who spoke on *Current Treatment Options for WM*.

Dr. Ma covered such topics as the criteria used for initiation of treatment, currently used treatment agents—alkylating agents, purine nucleoside analogs, immunomodulatory drugs, proteasome inhibitors, monoclonal antibodies, B-cell pathway inhibitors such as ibrutinib—for both frontline and relapsed therapy, their effectiveness and possible side effects, and the different types of responses to treatment. Afterward, patients were lining up to ask her more questions about various treatment options. Indeed, this is one of the most distinctive aspects of an Ed Forum—all the experts are approachable and willing to talk one-on-one to individual attendees and answer their questions.

Following a buffet lunch with healthy food choices (a very important part of menu planning for the Ed Forum!), Dr. Jorge Castillo of the Bing Center for WM at Dana-Farber Cancer Institute gave one of the Forum's most-anticipated presentations, *Treatments Around the Corner for WM*. Dr. Castillo and his team at the Bing Center typically see about 1,800 WM patient visits each year.

Dr. Castillo discussed newer proteasome inhibitors such as oral ixazomib (combined with dexamethasone and rituximab), second generation BTK inhibitors such as acalabrutinib and BGB-3111 (zanubrutinib), and a monoclonal antibody called daratumumab that targets CD38 and has the potential to remove the WM plasma cell compartment in the bone marrow. A great deal of interest was generated by his discussion of venetoclax, an oral inhibitor of BCL-2 that causes WM cells to die more quickly. The Bing Center is currently conducting a clinical trial of single agent venetoclax in previously treated WM patients and is seeing an overall response rate of 80% with relatively mild side effects. Venetoclax seems to be effective at clearing the bone marrow and appears to be working even in patients who were previously treated with ibrutinib or who have CXCR4 mutations. There are also some new combination therapies in discussion or already in clinical trials, such as ibrutinib plus rituximab, ibrutinib plus ulocuplumab (an antibody to CXCR4) in patients with CXCR4 mutations, and ibrutinib plus venetoclax in previously untreated WM patients. Although the latter study has not yet begun, Dr. Castillo anticipates that the combination will lead

to complete responses so that patients can go off treatment, rather than remain on treatment indefinitely.

Following a stretch break led by Stacy Kennedy of Dana-Farber to get everyone up and moving around to music, the group heard the last presentation of the day from Dr. Gwen Nichols, Chief Medical Officer of the Leukemia & Lymphoma Society (LLS), on *Clinical Trials and Why They Are Important*.

Dr. Nichols presented rather sobering statistics that 25% of clinical trials are not able to accrue enough patients to start, 25% are discontinued and do not reach conclusion, and only 3% of all adult cancer patients participate in trials. She also stressed that at no time is any cancer patient given only a placebo in a trial. Many times the care that a patient receives in a trial is better because of the close monitoring and additional testing required. She encouraged everyone to explore clinical trial opportunities and pointed out that LLS provides a service to help patients find the right trial for them. More information on this service can be found at <https://www.lls.org/treatment/types-of-treatment/clinical-trials>. Dr. Nichols also discussed database registries like WhiMSICAL and the new LLS registry under development as a means for increasing our knowledge about WM, its treatment outcomes, and patients' quality of life.

The attendees adjourned to various breakout sessions on focused topics such as *Caregivers* by Dr. Julianne Flora-Tostado, *Ibrutinib Treatment* led by Dr. Castillo, *Understanding Your Blood Tests* led by Dr. Matous, and *Peripheral Neuropathy* by IWMF Trustee Dr. Guy Sherwood.

Friday Night: A Chance to Relax and Socialize

Everyone gathered before dinner for drinks and hors d'oeuvres and the chance to socialize at the President's Reception. Moments like this throughout the weekend gave everyone the opportunity to share their stories and connect with so many others in the same boat. The Welcome Dinner featured the presentation of awards to some very deserving people. Honored this year with the Judith May Volunteer of the Year Award were a husband-and-wife team familiar to many, Don and Mary Brown. Don and Mary have led the Chicago Area Support Group for several years. Don has served as an IWMF Trustee, and Mary has volunteered at several Ed Forums. Laurie Rude-Betts spoke about the importance of the Ben

A Look Back, cont. on page 4





Judith May (center) poses with Don and Mary Brown, who received the 2018 Judith May Volunteer of the Year Award.

Rude Heritage Society, named for her late husband Ben Rude, the IWMF's second president, and presented awards to the newest members of the Society, Glenn and Marcia Klepac. A surprise award was given to our own Sara McKinnie in honor of her 20 years with the IWMF.

Saturday, May 19, Another Full Day in Store...

Saturday began very early for those with an interest in yoga who attended the Energizing Chair Yoga session led by Tracy Lester of Wellness House in Chicago. Saturday's buffet breakfast featured several hosted tables that people could freely join based on subjects of special interest, such as Newly Diagnosed, Caregivers, Watch and Wait, Young WMers, IWMF Connect, and the WhiMSICAL database. Following breakfast, the general sessions began with *Predisposition to WM: Overview and Current Updates* by Dr. Mary McMaster of the National Institutes of Health.

Dr. McMaster has been involved for several years in the study of familial WM and is looking at some of the factors that may lead to the development of the disease. While familial WM is rare, it is not as rare as first thought: up to 20% of WM patients report a family member with a related B-cell cancer and up to 5% report a family member with WM. Environmental and lifestyle factors do play a role in the disease, including chronic infections, autoimmune diseases, some chemical exposures, occupations such as farming, and certain lifestyle choices. Dr. McMaster emphasized the difference between germline variants (or mutations) in the germ cells (eggs and sperm) that can be passed down to children and somatic variants that are acquired in other body cells during one's life and cannot be passed down. The MYD88 mutation common in WM patients is a somatic variant. Individual germline variants by themselves are usually insufficient to cause cancer, and typically at least one other variant, such as a somatic one, must be acquired to cause cancer. It is likely that WM

results from a combination of events rather than one single cause. Dr. McMaster reiterated that even though the risk of acquiring WM in relatives of patients is increased, it is still a low absolute risk.

The day's second presentation was by Dr. Morie Gertz of Mayo Clinic Rochester, who spoke about *Unusual Conditions in WM*. Dr. Gertz's dry wit and practical wisdom have made him a popular speaker for many years on a variety of WM topics. This time he covered rare complications such as cold agglutinin disease, hemolytic anemia, cryoglobulinemia, neuropathy, amyloidosis, monoclonal gammopathy of renal significance, transformation to large B-cell lymphoma, and Bing Neel syndrome. These conditions are not typically found in most WM patients; most on this list are due to damage caused by unusual biologic properties of the IgM being produced by the WM cells of affected patients.

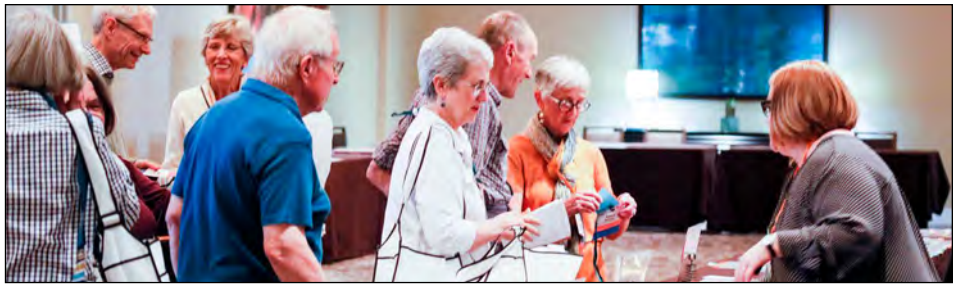
Another round of breakout sessions followed, including *Caregivers* by Dr. Julianne Flora-Tostado, *Share the Support Group Experience* led by Carl and Susan Stoel, *The I-Patient* moderated by Peter DeNardis and Andrew Warden, *Help in Choosing a Clinical Trial* by Alissa Gentile from LLS, and *What to Do About Cancer-Associated Fatigue* led by Dr. Lisa Wu of Northwestern University. The variety of breakout session topics on Friday and Saturday are all "pieces of the puzzle" that is WM, and they helped us gain a better understanding of the disease and ways to cope with it.

Saturday's buffet lunch featured Board Reports from several of the IWMF Trustees. Following lunch, the afternoon sessions began with Stacy Kennedy from Dana-Farber Cancer Institute, who discussed *Nutrition, Exercise, and Cancer*. Ms. Kennedy is a registered dietician who led a breakout session at the 2016 Ed Forum, and it was a good decision to bring her back for an energetic talk to the whole group.

Ms. Kennedy emphasized the importance of discerning the difference between "evidence-based nutrition" vs "Internet-based nutrition" and encouraged us to focus on the former. She provided dietary guidelines such as balancing your plate with 50% vegetables and fruit, 25% protein, and 25% whole grains. She suggested that folks who are undergoing treatment and have gastrointestinal issues should consider trying 6-8 small meals throughout the day rather than the traditional 3 big meals. She also listed several ways in which dietary adjustments can help with the side effects of cancer therapy such as nausea, changes in taste, diarrhea, and constipation. Ms. Kennedy discussed many of the common myths vs the truth about food choices and cancer. She also touched on exercise following cancer treatment and suggested that you should start slowly and pace yourself while you incorporate activity and exercise back into your life.

One of the highlights of the day was Dr. Steven Treon's presentation on *WM: Genomic and Treatment Advances*.

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Dr. Treon surprised the attendees by bringing Dr. Zachary Hunter and Dr. Guang Yang from the Bing Center to assist him.

Dr. Hunter opened with a discussion of the sequence of the events that led to the identification of the MYD88 L265P mutation in WM and its significance. He stressed that if your test results do not show this mutation, you should make sure you are tested for other variations in the MYD88 gene. This is because patients without MYD88 mutations (wild-type MYD88) appear to be somewhat clinically different from those with the mutations, and they may require different therapies. Dr. Hunter also discussed CXCR4 and other mutations in WM. He and others in the Bing Center group are actively working to determine how IgM MGUS progresses to WM. He discussed the Bing Center's new "300 Project," which is a plan to characterize the genome, epigenome, and proteome of 300 untreated symptomatic WM patients and follow them over time to understand various disease progression and treatment response patterns.

Dr. Treon took over the microphone to focus on the impact that discoveries in WM genomics are having in the clinical arena. A follow-up study of patients treated in the original Phase II trial of ibrutinib showed that the median progression-free survival had not yet been reached in most patients. But MYD88 and CXCR4 mutation status play a role in how long it takes for ibrutinib to work and how deep and long-lasting a response is achieved. Ibrutinib seems to have little impact on the IgA and IgG levels, in contrast to most other treatments like rituximab that tend to cause decreases. Dr. Treon also discussed Bing Neel syndrome and that he is seeing more WM patients with this than previously, although it is still rare. Bing Neel can be treated with a higher dose (560 mg/day) of ibrutinib. Dr. Treon discussed some of the newer BTK inhibitors and the newer combination therapies (ibrutinib/rituximab, venetoclax/ibrutinib, and ibrutinib/ulocuplumab) also mentioned by Dr. Castillo.

Dr. Yang concluded this presentation with a more in-depth discussion of his laboratory work with ibrutinib. There are no complete responses to the drug because, although it blocks BTK, it leaves the IRAK signaling pathway open. The Bing Center is looking at using an IRAK1 inhibitor called JH-X-119 in combination with ibrutinib as a way to cause more tumor cell killing and improve responses. He also touched on acquired resistance to ibrutinib. About six out of 100 patients eventually become resistant to the drug because of acquired mutations in BTK itself, and the Bing Center group is exploring drug strategies in the laboratory to overcome ibrutinib resistance in these patients.

With this presentation, the busy day concluded, and attendees were free to go on a leisure walk with Trustee Peter DeNardis or head to dinner on their own.

Sunday, May 20, the Ed Forum Concludes

All good things must come to an end, and the same is true for the Ed Forum. The intrepid souls among us trooped out early on a rather chilly spring morning for the second annual Walk for Waldenstrom's 5K. Unfortunately, the heavens opened up partway through the walk and thoroughly drenched the walkers, many of whom headed back to the hotel. There's always next year!

The first presentation on Sunday was *The Research Roadmap Roundup* from Dr. Stephen Ansell of Mayo Clinic Rochester, who has a knack for explaining complex concepts in easy-to-understand terms. He began by reiterating that WM is a disease with two problems: lymphoplasmacytic infiltration in the bone marrow and monoclonal IgM protein in the blood. While we understand much more about WM than we used to, there are still significant knowledge gaps in four basic areas: B-cell signaling pathways; "omics" such as variations in genes ("genomics") and variations in proteins ("proteomics"); immunology, or the ways in which we can mobilize our own immune systems to attack the cancer; and the bone marrow microenvironment, or the area that surrounds and nurtures the cancer cells. This is why the IWmf-LLS Strategic Research Roadmap Initiative has been developed—to encourage and fund research to fill these holes in our knowledge so that we can develop better treatments and a cure for WM.

One of the highlights of any Ed Forum is the *Ask the Doctor Panel*, which this year included Drs. Ansell, Castillo, Gertz, McMaster, and Treon. A very distinguished group! IWmf Trustee Dr. Guy Sherwood was the moderator and posed questions to the panel that were written down and submitted ahead of time by the audience and by members of IWmf Connect. It's always interesting to see the interplay among the panel doctors, and while many times they were in agreement, occasionally they were not. Unfortunately, space limitations preclude listing the panel questions and answers in this article, but the good news is that all the general session videos (and slides) from the Ed Forum are now or will appear soon on the IWmf website at <https://www.iwmf.com/multimedia>.

The Ed Forum came to an end just before noon with a few closing remarks from Dr. Sherwood. It's always a letdown to have to say good bye to people whom you've come to know at this and previous Ed Forums and with whom you share a special bond. But we have next year to look forward to! Be sure to mark your calendar now for the 2019 Ed Forum in Philadelphia to be held in the DoubleTree by Hilton Philadelphia Center City Hotel on June 7-9. Check your January 2019 *IWmf Torch* magazine and the IWmf website in early January for details.

<https://www.iwmf.com/news-and-events/iwmf-educational-forum>

PRESIDENT'S CORNER

BY CARL HARRINGTON

Closer Than Ever

Something special happened at the 23rd IWMF Educational Forum in Rosemont, IL. We had record attendance! Not by a little but by a lot. We had 373 attendees. That's 60 more WMers than our previous record. That's incredible for a rare disease like ours. For those of us who have been around a long time, it is nearly unbelievable to have that many WMers in one place. And attendees loved the Ed Forum. Overall, the rating was 4.82 out of 5. It's really hard to do much better than that!



The theme of the 2018 IWMF Educational Forum was *Imagine a Cure: Closer Than Ever*. Closer than ever to what you say? Well, not physically crowded together or closer than ever in the meeting rooms because of the record attendance but:

- *Closer than ever* to great support for newly diagnosed patients and caregivers no matter where they are in the world
- *Closer than ever* to better treatments for WM with fewer side effects and longer remissions
- *Closer than ever* to understanding WM and finding a cure

The IWMF was founded in 1994 and incorporated in 1998. In 1994, Arnie Smokler, a retired pharmacist in Washington DC who had WM, wrote to the National Organization of Rare Diseases (NORD) in search of fellow WMers. Remember this was before HIPAA, the Health Insurance Portability and Accountability Act of 1996, before the Internet, and before there was even a standard definition of what WM was. Fortunately, writing, ink, and the Post Office had been invented. NORD wrote back and gave him the names of 21 people with WM. Can you imagine that happening today? Arnie wrote to each person and they all wrote back; this little group started what is now the IWMF. Today we have over 10,500 members from over 70 countries. More members mean more power, more resources, more clout, and more chances we'll get to a cure.

In 1994, no one had any idea what life expectancy was for someone diagnosed with WM. When I was first diagnosed with WM in July of 2006, I was very, very worried about my future. At the time, the posted survival rate was 3 to 5 years. That later grew to 6 to 10 years, but now I'm hearing Dr. Treon and Dr. Castillo of the Dana-Farber Cancer Institute talk about 16 to 20 years from the date of diagnosis. Sixteen+ years!

Since the average age of diagnosis is in the mid-60s, this means closer to the average life expectancy for many WMers.

At the Ed Forum, all the WM patients attending had ribbons on their nametags that identified how long they had been living with WM. So that everyone could get a sense of who was there, I had everyone with WM stand up and then sit down in order of how long they had been living with WM. At the end, we got to the group who had been living with WM for 20 years or more. We had 12 people still standing. All of these folks were diagnosed during the last century, which was pretty reassuring to all of the newly diagnosed attendees. But even better, we did a little research in our database and found we had (drum roll, please) 202 WMers in our database who were diagnosed 20 or more years ago. And we don't even have diagnosis dates for a big percentage of our members. (Hint, if you're not sure if we have your date of diagnosis, most current address or email, or date of birth, please mail your information to the IWMF office to the attention of Jennifer Silva or email her at jsilva@iwmf.com.)

How is this great progress in life expectancy happening? In 1994, we had four treatments. Now it's hard to count, but we have at least 30, including ibrutinib, the first and only drug approved by the FDA for WM. And these treatments *are better with fewer side effects and deeper, longer remissions*.

And we have a lot more treatments coming. Be on the lookout in the *IWMF Torch* for the Medical News Roundup column, in the presentations from the Ed Forum, and on our website for news of new treatments including:

- venetoclax
- acalabrutinib
- zanubrutinib
- ulocuplumab
- ixazomib
- daratumumab
- oprozomib
- obinutuzumab
- carfilzomib

By the way, if you were not able to come to the Ed Forum in Rosemont, all of the presentations and the PowerPoint slides are now or will soon be available on our website in the Multimedia section.

Why do we have so many new drugs in the pipeline and how come there is so much interest in a rare disease like WM? Well, it's partly because of what we've done together. Since 1999, the IWMF has funded over \$12.2 million in WM research for over 40 specific projects. Every single one of

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those dollars has come from WM patients, family, and friends. If you haven't already done so, ask your friends and family help you support the IWMF!

Today we have over \$5 million invested in 13 active projects around the world. This means when you get up in the morning, research directed towards WM's remaining secrets is going forward. While you are having dinner, another laboratory is the site of other specialized doctors and researchers pushing to find a cure for your disease. And even when you go to bed, the drive for success is still on!

Another way to say that is: The sun never sets on WM research!

The sun also never sets on IWMF support. We now have affiliates in 18 countries outside of the US. We have over 65 support groups globally, and our materials are translated into seven languages and are available for free on our website. And, of course, our website can be viewed in over 100 languages with Google Translate.

You may have noticed that the name of our organization is the IWMF. That "I" stands for International. We now have 18 international affiliates. Well, that's really 19 if you count us here in the US. For comparison, you might remember we started with 21 PEOPLE in 1994. Now we have nearly that many COUNTRIES. Overall, we're now in countries that contain nearly 50% of the world's population of 7.6 billion people.

I'm proud to say that we had the affiliate leaders at the Ed Forum from Australia, Canada, China, India, Mexico, and the UK.

To help you see how far we've come since the beginnings of the IWMF, here's a chart that shows how we're *closer than ever*.

How the IWMF is Closer Than Ever		
Element	1994	2018
# of members	21	>10,500
# of countries	1	> 70
Life expectancy	?; then 3-5 years	16-20 years
# of treatments	4	30+
IWMF funded research	0	> \$12,200,000
Affiliates	0	18
Support Groups	0	>65
Languages	1	7



Front row: Rajini Seroo (co-leader: India), Allison Brown (Roger Brown's wife: UK), Elena Malunis (vice president for Member Services and chair of International Committee)
Back row: Carl Harrington (president, IWMF), Roger Brown (UK), Polo Pena (Mexico), Roger Yao (China), Betty McPhee (support group leader: Canada), Saurabh Seroo (India), Andrew Warden (Australia)

Closer Than Ever is actually the name of a brilliant musical by Richard Maltby, Jr., and David Shire. Written in 1989, each song is a unique story told by a new character dealing with topics such as aging, mid-life crises, second marriages, relationships between working couples and between parents and adult children, responsibilities, and unrequited love. And yet, the lyrics to the final song, *Closer Than Ever*, are appropriate for us, especially when we support each other, as the IWMF does so well.

*Well, what d'ya know, a door locked tight
Opens at last and shows some light...
But strange as it seems, it took the pain
To bind us together
Closer than ever.*

If you weren't able to come to the IWMF Ed Forum in Rosemont, we're bringing it to you! Once again, check the presentations and the PowerPoint slides that are now or will soon be available on our website in the Multimedia section. See for yourself how we're *closer than ever*.

I hope to see many of you at our next IWMF Educational Forum June 7-9, 2019, in center city Philadelphia at the DoubleTree Hilton Hotel.

Stay well!

LIFELINE: THE IWMF'S BEST KEPT SECRET

BY LISA WISE

It wasn't a feeling of being "physically" alone. Family, friends, neighbors, and community members all wanted to help after learning of my diagnosis. Their well-meaning inquiries were heartfelt as they strived to identify how best to offer support. There was only one glaring problem. I had no idea what support I actually needed.

I was absolutely certain about what I did NOT need. I did not need tuna casseroles left on my doorstep; visitors at my 10-hour marathon chemo sessions; sad, puppy-dog eyes greeting me when I ran into friends at the grocery; or "inspiring" talks about the power of cosmic kismet.

Thankfully, the IWMF helped teach me about what I really DID need: support from other WMers. Being able to genuinely connect with others who share this same rare and unpronounceable disease makes me feel less alone in my diagnosis. It allows me to tap into just the right kind of connection at every curve in the road. When it comes to support, the IWMF knows that one size does not fit all.

As we navigate through our unique journeys, the IWMF offers a full range of support services that perfectly match what is most needed at each given touchpoint. Through the IWMF, experienced volunteers flexibly offer "just in time" support to their fellow WMers.

When first diagnosed, I was on "watch and wait" and living in Silicon Valley. It made cultural sense to instantly hop online and join the highly informative virtual community of IWMF Connect from the ease of my laptop. After moving to Philadelphia, my symptoms slowly increased, and it felt right to attend a nearby, welcoming IWMF support group in person. As a budding support group leader, I was invigorated and empowered to participate in my first IWMF Ed Forum in Dallas. When it was time to begin treatment, I craved concrete advice from a knowing, caring, experienced, compassionate fellow patient who had walked the exact same chemo path and knew the journey ahead firsthand. It was the perfect moment to call IWMF LIFELINE.

The only problem was: I did not even consider calling LIFELINE.

In truth, it may have been the name that discouraged me. "LIFELINE" sounded like a service to use only in case of emergency, in total desperation. Perhaps I shied away from reaching out to a total stranger, somewhere across the country. Thankfully, a very wise friend (okay, Carl Harrington) sensitively suggested that before I begin treatment, I pick up the phone and call several LIFELINE volunteers to hear about their experiences. Thankfully, I listened and learned SO much from each of the five volunteers that I contacted. Their advice, guidance, and empathic support prepared me for my treatment in invaluable ways.

When I reached out to Vicki Marino, a deeply dedicated LIFELINE volunteer, her caring and compassionate ways helped me through treatment. A complete stranger before I called—and we have yet to meet!—our connection continues to grow, and she is now a treasured Waldenfriend. Her thoughtful and supportive messages guided me:

"I'm so glad we had a chance to talk before your first treatment. We are so fortunate to have support groups and other WM patients to contact with questions and just plain moral support. All of us are different with this disease, and our journeys are different as well. You may feel like resting all weekend after this first treatment like we talked about. The beginning of anything takes some getting used to and by the end you'll be a pro. I know you will do great, and please call me anytime you have a concern or just need a pep talk!"

Each LIFELINE volunteer that I contacted was uniquely helpful. They all offered different perspectives but shared one common goal: a genuine desire to help me navigate my way through my WM journey, armed with as much information, education, support, and guidance as possible. Their timely advice included: tips on infusion day self-care; strategies for communicating and advocating preferences to my team; key questions to ask before that first infusion; the importance of expert second opinions; and setting realistic expectations for recovery. Beyond that, they gave me a glimpse of life *after* treatment, a sneak peek into their world of post-chemotherapy "normalcy." They gave me hope. On the anxious eve of my first treatment, hope was truly priceless.

What is LIFELINE?

IWMF'S LIFELINE is a volunteer-based service offering personalized, confidential, one-to-one communication through phone or email, to address your specific WM questions. It is ideal for those wanting to connect with experienced WMers offering guidance in specialty areas. Conveniently, this connection can be made from the comfort of your own home at a time that is best for you. By picking up the phone or sending off a quick email, you can connect to another WMer in real time.

It is rare in this technological world of ever-increasing automation to benefit from the sound of a compassionate human voice on the phone or a warm virtual link to another fellow patient or caregiver. Sharing a moment of genuine connection is powerful. Although this disease may offer varying symptoms, treatments, and impacts on our lives, we all strive to learn how to navigate the waters knowledgeably and thoughtfully, without becoming overwhelmed. LIFELINE volunteers offer reliable information in a supportive manner

Lifeline: The IWMF's, cont. on page 10

and can address questions and concerns about a wide range of WM topics, treatments, and therapies.

Who Are LIFELINE Volunteers?

LIFELINE has a team of dedicated volunteers comprised of friendly and knowledgeable WM patients and caregivers who are willing to share their extensive experiences in order to help others. Over 55 different LIFELINE volunteers consult on 40 different specialty topics. Although these volunteers are primarily US-based and English speaking, there is also an international LIFELINE, and some of the IWFM's international affiliates provide a LIFELINE service in other languages. This committed team ensures that the right volunteer is ready to offer warm support and useful guidance when needed.

What Happens on a LIFELINE Call?

LIFELINE volunteers listen carefully, share their own experiences when helpful, and offer useful guidance and caring support. LIFELINE volunteers are not usually doctors, nurses, or medical professionals, and therefore do not give medical advice or treatment recommendations. However, they do have extensive personal experience on the topic(s) that they support and can assist in accessing better information and suggest referrals to specialized experts, when appropriate.

Whether you are curious about venetoclax, managing fatigue, living with peripheral neuropathy, seeking to connect with a fellow caregiver, beginning a course of treatment, or considering a critical second opinion, LIFELINE can help. One new topic, the "Twenty Years Club," features five fabulous volunteers who have been living and thriving with WM for the past 20 years. They offer a generous dose of inspiration and an uplifting perspective from decades of WM experience. From newly diagnosed patients to seasoned WMers, LIFELINE offers something for everyone.

Why is LIFELINE the "Best Kept Secret?"

LIFELINE is a terrific way to access support, information, and education right from the comfort of your own couch. Hearing the helpful voice of a fellow WMer can make all the difference in the world. Please help spread the word!

In closing, I am not only a frequent user and huge fan of LIFELINE, but also the proud LIFELINE committee chair. I welcome the opportunity to hear about your experiences so please reach out to me at wiseplace@gmail.com. Have you used the service? If so, what worked? What needs improvement? Which hot topics would you like added? Your ideas and feedback are essential as you are an invaluable part of the wonderful IWFM support network.

I am ever indebted to the extraordinary LIFELINE volunteers who generously give their time and support toward easing the path of fellow WMers. What inspires LIFELINE volunteers to selflessly give back in this meaningful way? Enjoy these moving words from an inspiring LIFELINE volunteer:

"My day stops when a call or email arrives from someone with WM. I know what it feels like to be scared with this disease, and I will do what I can to alleviate that suffering... I love connecting with those who contact me, no matter their circumstances. I love hearing how their fear diminishes in their voices. I always say: 'I'm available and stay in touch' so they know that they are not alone. Ultimately, I hope they feel encouraged enough to give back to the next individual facing issues with WM."

Check out the link below and consider calling or emailing a LIFELINE volunteer today!

Wishing you a world of wellness on your WM journey.

How Does LIFELINE Work?

Step 1. Have a question about a WM-related topic or treatment?

Step 2. Check out the LIFELINE Directory on the IWFM website:

https://www.iwfm.com/sites/default/files/docs/documents/IWFM_LIFELINE.pdf

Step 3. Call or email a specific LIFELINE volunteer to connect to support.

Step 4. Enjoy a one-on-one conversation with an experienced, knowledgeable, understanding, and compassionate fellow WMer.

Confidential peer support is just one of the many free services brought to you by the IWFM.



IWMF DOC STAR: STEPHEN ANSELL

EDITED BY RON TERNOWAY



Dr. Ansell speaking to an Ed Forum attendee

Growing up in Pretoria, South Africa, teenager Stephen Ansell dreamed of becoming a nuclear physicist, “mainly because it sounded like an extremely important job.” Once he understood exactly what the profession entailed, however, he was less enthusiastic about it.

An opportunity arose to shadow a family friend who was involved in veterinary research. While Ansell found animals extremely interesting, “I found studying people far more compelling. I grew up during the apartheid era in South Africa and as I got older I found myself very bothered by the segregation I saw all around me. I felt challenged to do something that would benefit all members of society.

“Rather than going directly into research, I was advised to first do medicine and do research later. This proved to be very good advice.” Dr. Ansell received his medical degree at the University of Pretoria and subsequently completed his PhD at the same institution. He specialized in medical oncology before coming to the United States in 1994, where he completed a residency in internal medicine and a fellowship in hematology and oncology at Mayo Clinic, Rochester, MN.

His first winter in Minnesota was quite mild, and he initially thought people might be exaggerating about the cold. The second year had record cold temperatures and was a “baptism by fire” (or maybe ice?).

He is currently professor of medicine, Mayo Clinic College of Medicine, consultant in the Division of Hematology, Department of Internal Medicine, and chair of the Mayo Clinic Lymphoma Group.

Dr. Ansell has been honored with various awards during his training and career, including the Department of Medicine New Investigator and Faculty of the Year at Mayo Clinic and

Medical Honoree at the Lymphoma Research Foundation, Minnesota Chapter.

He has served on the editorial boards of the *American Journal of Hematology*, *Journal of Clinical Oncology*, *Blood Cancer Journal*, and *Clinical Lymphoma and Myeloma*. He is the co-author of more than 340 articles in peer-reviewed journals.

Ansell is chair of the IWMF Scientific Advisory Committee and a member of the Scientific Committee of the Leukemia & Lymphoma Society. He regularly speaks at IWMF Educational Forums, and in 2016, 2017, and 2018 delivered updates on the IWMF-LLS Strategic Research Roadmap. He has been a member of the Ed Forum Ask the Doctor panels for several years.

Reflecting on his career to date, Ansell is quick to credit the professionals who helped him on his way. “In South Africa, the head of the Department of Oncology at the University of Pretoria, Geoffrey Falkson, got me interested in clinical trials and created an opportunity for me to do a PhD. After coming to Mayo Clinic, Diane Jelinek, a B-cell biology researcher, provided me with research space in her lab, and colleagues in the Lymphoma Group, Tom Witzig and Tom Habermann, were very supportive.”

And how does he feel about the Mayo Clinic? “There is an impressive collegial attitude at Mayo Clinic, and the degree to which researchers and clinicians work together is quite remarkable. This really allows the institution to focus on the needs of the patient both clinically and in research.”

So how successfully are the needs of patients being met? “My greatest reward is to see patients with B-cell malignancies responding to treatment and living longer with these diseases. My greatest challenge, however, is to convert all B-cell cancers into curable diseases rather than managing many of them as chronic diseases.

“I would encourage Waldenström’s macroglobulinemia patients to be very hopeful. The prognosis has improved dramatically and continues to improve every year. I am extremely optimistic that a cure for this disease will be found in the not too distant future.”

Meg Mangin, WM patient and regular contributor to both IWMF Connect and the IWMF Facebook page, was in dire straits when she first consulted Dr. Ansell. She had been obliged to discontinue her Imbruvica therapy after suffering a rare and serious side effect: liver toxicity. As a result of stopping the drug, she immediately relapsed, with skyrocketing IgM, drenching night sweats, and significant weight loss. Her local oncologist referred her to Mayo Clinic and to Dr. Ansell.

IWMF Doc Star, cont. on page 12

"I was impressed with his ability to facilitate blood tests, PET scan, GI consult, liver biopsy, plasmapheresis, bendamustine infusions, and two follow-up visits—all that same week! Dr. Ansell's competent handling of this complex situation affirmed my confidence in his expertise. I felt well-informed, and he included my husband in our discussions.

"Dr. Ansell has an excellent 'bedside' manner," she added. "He speaks quietly with a charming South African accent and his demeanor is friendly, calming, and respectful. When I expressed my extreme reluctance to undergo a liver biopsy, he patiently explained the reasons for his recommendation, but he also gave me permission to opt out.

"My nursing career has taught me the importance of being proactive to receive the best medical care. Dr. Ansell has my complete trust because his actions have demonstrated compassion and professionalism at the highest level." Meg's capsule summary: "I'm very thankful to be under his care."

When Ansell's white coat comes off, it's time for some of that work-life balance: "It is extremely important for me to have

interests different from what I do at work. I like to participate in and watch sports, particularly soccer and tennis," he said.

"I am married with two children. My daughter completed her master's degree in counseling this spring and is newly married. My son is finishing a degree in engineering. My wife is very active in the music program at our church. All of my family members (except me) are very musical, and I get to enjoy listening to whichever band or choir they participate in.

"I also enjoy travel and get to do more of this with my wife now that we are empty nesters.

There are so many wonderful places around the world. I think the place where we had the most fantastic experience was Machu Picchu in Peru."

A parting word from the good doctor about our favorite foundation: "My research has benefited substantially from funding obtained from the IWMF. Without this support, the work that I have participated in would not be possible. I am extremely grateful for the support I receive from the IWMF."

WHAT YOU SHOULD KNOW NOW ABOUT CHARITABLE GIVING IN 2018

Knowing that most WMers are inquisitive and searching for information about their disease, we thought you would appreciate some information regarding changes brought about by the Tax Cuts and Jobs Act 2017. We also understand that most of your giving is motivated by charitable causes, not by tax savings. However, understanding tax savings allows you to maximize your giving. The changes brought about by this tax reform may cause you to rethink how you structure your charitable giving. We wanted to share this information with you now so that you have a chance to review your options, and if necessary, make some changes that will allow you to benefit your family and impact the work and future of the IWMF.

The changes in the tax law make charitable giving from IRA assets more desirable for more tax filers. Given the average age of WMers, we assume that a significant percentage have established IRAs or some other form of tax-deferred retirement fund. We also know that 70 to 80% of the population eligible for qualified-plan distributions take the distribution between October 15 and Thanksgiving of each year. The possibility of gifting from this pool of assets could have a positive impact on those in any income category.

The new lower income tax rates suggest that most, but not all, will have a lower tax obligation in 2018. The basic component of the change is the higher standard deduction now at \$12,000 per individual plus an extra \$1,300 deduction if over 65. So a couple over age 65 could have a total deduction of \$26,600.

The Act also includes several provisions modifying itemized deductions or suspending them beginning with this year. In addition, the aggregate deduction for state and local income, sales, and property taxes is limited to \$10,000 under the Act. For higher income families, many deductions phase out as income increases.

These changes mean that fewer taxpayers will itemize their deductions in 2018 because the standard deduction is increased, while several significant deductions are reduced or eliminated. Last year about 26% of filers were itemizing, whereas this year only about 11% are expected to do so.

The IRA rollover is a gift from an individual retirement account (IRA) which is called a Qualified Charitable Deduction (QCD). You must be age 70½ (by December 31) to utilize this option, and the gift must come directly from your IRA. The IRA rollover effectively operates as a universal

What You Should, cont. on page 13

deduction (meaning an “above the line” deduction). The impact of this type of gift is **exclusion of income** and it may be the best gift for many donors.

Many nonitemizers can use this to take advantage of the equivalent of a double deduction. They can claim the standard deduction and make IRA QCD gifts to reduce taxable income. It is also an excellent option for itemizers, as exclusion of income, or income reduction, may provide a benefit for those who are bumping up against some of the percentage limitations. QCD gifts can be any amount up to \$100,000 per account holder. This type of gift can be made to a variety of qualified charities that you support, including the IWMF.

If you have a qualified plan or tax deferred plan that is not an IRA, such as a Keogh, 401K, or 403B, then you might consider setting up an IRA account and transferring assets from your current account to the IRA account. In most instances this will be a nontaxable transaction. It is only an IRA QCD gift that can be transferred to charity without triggering taxable income. You should also be aware that there is no income tax deduction for an IRA QCD gift, but exclusion of income provides the equivalent benefit.

For those who do itemize, another provision of the Act is that the deduction limit for charitable gifts has been raised to 60% (for cash gifts) of adjusted gross income (AGI) from the 2017 level of 50%.

As itemizers, you may want to consider gifts of appreciated assets such as publicly-traded stock or real estate. Consider a Charitable Swap to maintain your same portfolio. Instead of giving cash to charity, make a gift of highly-appreciated stock and take the cash you would have given to charity and use it to immediately purchase identical stock replacing the donated shares. The charitable swap wipes out all capital gains taxes on appreciated stock. There is a double benefit in gifting appreciated assets such as stock: you avoid the capital gains tax that would be due if the stock were sold, plus you receive a charitable income tax deduction for the fair market value of the stock on the date of the gift.

If you have made provisions or are thinking about providing for charities as part of your estate plan, then establishing a charitable remainder trust may be a prudent option. Charitable remainder trusts provide income to the donor or other noncharitable beneficiaries, with the remainder going to charity after a term of years or a lifetime. The charitable remainder trust is irrevocable, but the donor can reserve the right to change charities. The trust creates a charitable deduction in the year of the gift based on actuarial computations. The trust is tax-exempt, so it avoids capital gains tax on the liquidation of the property. It is often possible to increase income off a low basis asset, avoid capital gains tax, and create an income tax deduction which is subject to a 30% limitation of AGI but can be combined with other cash

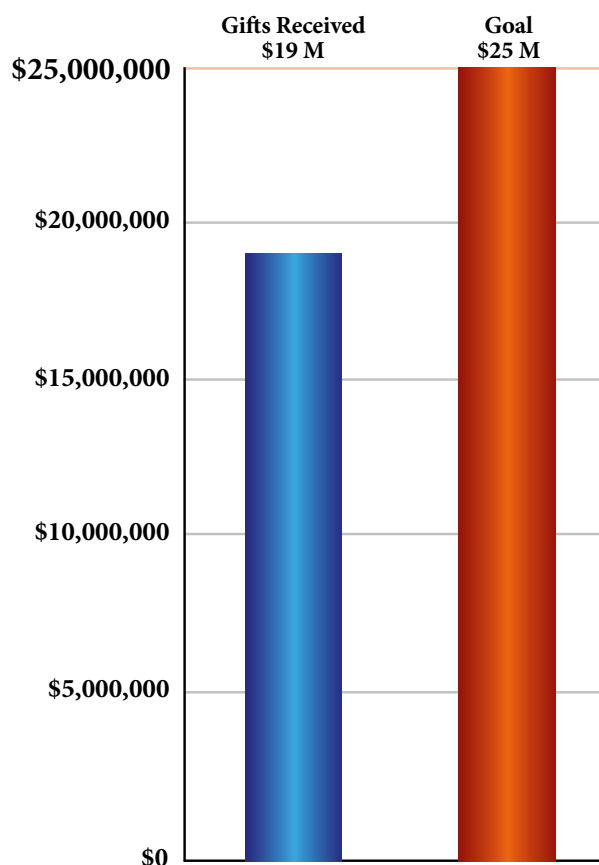
gifts. The income tax deductions are often more than can be used in a single year, but the law allows a deduction for the year of the gift plus five years of carry forward. These trusts can be established to benefit several charities including the IWMF.

There are other gifting options including: the power of bunching charitable deductions—bunch your gifts and claim the deduction one year; use the standard deduction the next year; pay off pledges early or prepay gifts for future years; or establish a Donor Advised Fund (DAF).

Many of these gifts can be modeled based on your circumstance. We would be pleased to visit with you about options that might be of interest. We can prepare gift models that you can review and, if interested, take them to your financial or legal advisers to determine if the particular option might be appropriate for your circumstance.

The information included here is not intended as professional tax or legal advice. Consult a tax advisor about your specific situation.

Imagine a Cure Campaign Progress Report as of April 30, 2018



RESEARCH PARTNERS

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

David and Janet Bingham Research Partners Fund of the IWMF

Elting Family Research Partners Fund of the IWMF

Robert Douglas Hawkins Research Partners Fund of the IWMF

Michael and Rosalie Larsen Research Partners Fund of the IWMF

Carolyn K. Morris Research Partners Fund of the IWMF

K. Edward Jacobi Research Partners Fund of the IWMF

Marcia Wierda Memorial Research Partners Fund of the IWMF

NAMED GIFT FUNDS

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

Baker Family Research Fund of the IWMF

Yoshiko Button Member Services Fund and Research Fund of the IWMF

Friedlander-Scherer Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Dr. Robert Kyle Research Fund of the IWMF

Lynn Martin and Carrie Wells Research Fund of the IWMF

Dennis and Gail Mathisen Research Fund of the IWMF

Gail Murdough Member Services Fund and Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

Donald and Kathryn Wolgemuth Research Fund of the IWMF

If you have discretionary giving power and would like to help move our research program forward in a special way we invite you to join those listed above. For more information about Research Partners and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Dave Benson, IWMF Senior Development Officer, at (952) 837-9980 or dbenson@iwmf.com

JAMES HINCHCLIFFE RIDES FOR IWMF



The Hinchcliffe team: James Hinchcliffe (second from left), John DeLong (fourth from left), and Scary Harry (easily recognized in his orange harness)



James and John heading for the starting gate

On April 27, Verizon IndyCar Series driver James Hinchcliffe held the winning reins in a competition of four drivers vying for a monetary prize of \$1,500 to be donated to a charity of the winner's choice. James named the IWMF to be his designated charity, and we all thank him for this very generous gesture.

Wait a minute! "Winning reins"? How does this describe the track victory of a well-known IndyCar driver? The answer is that James was the winning driver in a race very different from his usual challenges. On this occasion, James joined three of his fellow Verizon IndyCar Series drivers as competitors in an event billed as "Celebs in the Sulky" and described as the first-ever IndyCar celebrity horse race for charity.

Although none of the four drivers had previous experience driving in a harness racing event, all were game to compete for the charity of their choice. To keep the competition "on track," each IndyCar driver was paired with a professional driver of the Hoosier Park Racing & Casino in Anderson, IN, where the event took place. James rode in the sulky with professional driver John DeLong behind a handsome chestnut gelding with the daunting name of Scary Harry.

When the four horses pulling the paired drivers hit the 7/8 mile track, pebbles flew through the air. It was an exciting event, especially when Scary Harry came from behind in the home stretch and pushed on to victory for James and John.

Asked why he chose to direct the prize he won to such a small cancer organization as the IWMF, and one devoted to a little-known cancer at that, James Hinchcliffe replied as follows: "WM is a disease that has affected our family personally, my grandfather having been diagnosed. My family has since been huge advocates of fundraising for WM. My mother started the WMFC in Canada, and more recently we've partnered with other charities in events to help the WM cause. Any chance I get, I am happy to help! I'm thrilled we won the race and were able to get a few dollars to the IWMF"



*The full field of Verizon IndyCar drivers seated in their sulkies at the exciting moment when Scary Harry broke from the rail and headed into the homestretch
Photos by Chris Bucher (@bucherphoto)*

MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

Ibrutinib in Capsule Form Reinstated as a Dosing Option

– Pharmacoclics announced that ibrutinib (Imbruvica) in 140 mg capsules will continue to be offered as a dosing option. Earlier this year, a once-daily, single-tablet formulation was introduced in the US in different strengths of 140 mg, 280 mg, 420 mg, and 560 mg in a 28-day blister pack that was intended to replace the capsules, which were to be discontinued after May 15, 2018. Because of price and dose modification concerns raised about the new single-tablet formulation by patients, physicians, and patient advocacy groups (including the IWMF), the 140 mg capsules in a 90- or 120-capsule bottle will still be available to ibrutinib patients in the US, along with the new tablet formulation. Patients are encouraged to discuss with their physicians which formulation, capsule or tablet, best suits their needs.

Memorial Sloan Kettering Study Looks at Infectious Diseases in Patients on Ibrutinib Therapy

– Memorial Sloan Kettering Cancer Center conducted a retrospective review of the medical records of patients with lymphoid malignancies at its institution who received ibrutinib (Imbruvica) during a 5-year period from January 1, 2012, to December 31, 2016, to determine the incidence of serious infections in this population. The most common underlying malignancies were chronic lymphocytic leukemia and mantle cell lymphoma. The study, published in the journal *Clinical Infectious Diseases*, identified 378 ibrutinib patients, 43 of whom (11.4%) developed serious invasive infections. These types of infections, present in the blood, spinal fluid, or other normally sterile sites, occurred primarily during the first year of ibrutinib treatment. The infections were bacterial in 53.5% and fungal in 37.2% and resulted in death in six of the patients (14%).

Mayo Clinic Publishes Its Study Results on Infectious Diseases Associated with Ibrutinib Treatment

– Meanwhile, researchers at the Mayo Clinic in Phoenix have published a report in the journal *Blood Reviews* with similar findings to those above, estimating that up to 10% of patients on ibrutinib (Imbruvica) have a risk of developing serious infections and noting that among randomized Phase III clinical trial participants receiving ibrutinib, serious infections were seen in up to 24% of patients. The Mayo researchers suggested that an off-target effect of ibrutinib inhibits the development of T-cells, which are important in the pathogenesis of certain infections. The Mayo team recommended close monitoring of patients starting ibrutinib treatment and individualized prophylactic therapies to reduce the risk of infections, especially fungal and *Pneumocystis* infections. They advised baseline hepatitis B virus serology testing for patients starting ibrutinib treatment, further recommending that patients with chronic hepatitis B should be considered for prophylaxis

with the oral drug entecavir (Baraclude). Vaccinations against influenza and *Streptococcus pneumoniae* were also recommended, and the researchers noted that the new shingles (herpes zoster) vaccine Shingrix appears to be safe in immunocompromised individuals and is likely to become a standard preventive strategy for shingles in this population.

New Clinical Trial to Study Ixazomib and Ibrutinib Combination in WM

– The Mayo Clinic in Jacksonville is planning to open a Phase II clinical trial using the combination of ixazomib (Ninlaro) and ibrutinib (Imbruvica) in relapsed/refractory WM. The study anticipates enrolling 47 participants to assess the efficacy and safety of the combination. Participants will receive ixazomib, which is an oral proteasome inhibitor, on days 1, 8, and 15 and ibrutinib daily on days 1-28 of each cycle. The treatment will repeat every 28 days for up to 24 courses in the absence of disease progression or unacceptable toxicity. On www.clinicaltrials.gov, the trial identifier is NCT03506373.

Pembrolizumab (Keytruda) to Be Assessed in Clinical Trial for Indolent NHL

– Fred Hutchinson/University of Washington Cancer Consortium in Seattle was scheduled to open a Phase II clinical trial of pembrolizumab (Keytruda) on May 16 for the treatment of indolent B-cell non-Hodgkin's lymphoma, including WM/LPL (lymphoplasmacytic lymphoma). The study is expected to enroll 33 patients who have not been previously treated. Pembrolizumab is a humanized monoclonal antibody therapy that targets the programmed cell death 1 (PD-1) receptor of lymphocytes. Participants will receive pembrolizumab intravenously over 30 minutes on day 1, and treatment will repeat every three weeks for up to 18 courses. The trial identifier number on www.clinicaltrials.gov is NCT03498612.

Gilead Sciences Reports Preliminary Results for New Combination Therapy in CLL and Lymphoma

– Gilead Sciences has reported preliminary results for a Phase Ib clinical trial evaluating the safety and tolerability of the BTK inhibitor tirabrutinib (in the same drug class as ibrutinib) combined with the SYK (spleen tyrosine kinase) inhibitor entospletinib in 32 enrolled patients with previously treated chronic lymphocytic leukemia and several types of lymphoma. So far, the study includes five patients with WM. After 22 weeks, 26 of the patients remained on treatment. The most common side effects included fatigue, petechiae (small red or purple skin spots due to bleeding), weakness, constipation, bruising, indigestion, neutropenia (low number of neutrophils), and rash. No patients discontinued treatment because of side effects. Of the 17 patients evaluable for response, 11 had a partial response, 4 had stable disease, and 2 had progressive disease. The trial is still recruiting

Medical News Roundup, cont. on page 17

patients, and the identifier number on www.clinicaltrials.gov is NCT02457598.

Rituximab Efficacy Is Enhanced in Combination with Experimental Agent – The combination of rituximab (Rituxan) and the experimental agent ALT-803 led to a response rate of 48% in patients with relapsed or refractory indolent non-Hodgkin's lymphoma, according to preliminary data from a Phase I/II study presented at the American Association for Cancer Research (AACR) Annual Meeting in April 2018. ALT-803 is a compound that mimics the effects of interleukin-15 (IL-15), an immune system activator that enhances the survival and anti-cancer activity of the body's own T-cells and natural killer (NK) cells. Preclinical studies showed that ALT-803 improved the efficacy of anti-CD20 monoclonal antibody therapy such as rituximab. The 21 patients in the Phase I part of the trial were treated with rituximab and ALT-803 once a week for four weeks. Those who responded were then given a treatment of both drugs every eight weeks for an additional four cycles. The most common adverse effects were high blood pressure, anemia, nausea, fever, chills, high blood sugar levels, and neutropenia (low number of neutrophils). The Phase II part of the trial is open to patients with WM and is being conducted in Minnesota, Missouri, Ohio, Pennsylvania, and South Carolina. The trial identifier number on www.clinicaltrials.gov is NCT02384954.

New Antibody Drug Conjugate Targets CD74 in B-Cell Malignancies – Sutro Biopharma has begun a Phase I clinical trial of its antibody drug conjugate STRO-001 that targets CD74, a protein highly expressed in B-cell malignancies. Sutro expects to enroll up to 220 non-Hodgkin's lymphoma and multiple myeloma patients who are refractory to treatment and will conduct the trial at approximately 50 sites in the US and Europe. An antibody drug conjugate (ADC) links a monoclonal antibody therapy with a cytotoxic drug that kills cancer cells and is therefore a highly targeted therapy. STRO-001 will be administered intravenously on day 1 and day 15 of each 28-day cycle. The trial identifier number on www.clinicaltrials.gov is NCT03424603.

Shingrix Vaccine for Shingles Approved in Europe and Japan – The European Commission and the Japanese Ministry of Health, Labor and Welfare have approved the Shingrix vaccine for the prevention of shingles (herpes zoster) for adults aged 50 years and older. Shingrix was approved in 2017 in Canada for the same population; it was also approved in the US in 2017, but for immunocompetent adults aged 50 years and older. Shingrix is the first approved non-live shingles vaccine.

Health Canada Approves Subcutaneous Rituximab for CLL – Health Canada recently approved a subcutaneous formulation of rituximab (Rituxan) for patients with chronic lymphocytic leukemia (CLL). The administration of subcutaneous (SC) rituximab takes only seven minutes, as opposed to the several hours necessary for intravenous (IV) administration. The approval was based on data from the Phase Ib multicenter SAWYER study of 176 patients with previously untreated CLL who were treated with rituximab in combination with chemotherapy. This trial showed an overall response rate of 85.2% for the SC formulation at the end of frontline therapy, compared to 80.7% for the IV formulation. Local cutaneous reactions, including injection site reactions such as redness, pain, and swelling, were reported in up to 42% of patients. These reactions were most common during the first cycle and decreased with subsequent injections. No cases of severe hypersensitivity reactions were observed.

Duvelisib Advances in FDA Approval Process for CLL/SLL and Follicular Lymphoma – The US Food and Drug Administration (FDA) has granted Priority Review to duvelisib for patients with chronic lymphocytic leukemia (CLL)/small lymphocytic leukemia (SLL) or follicular lymphoma. The drug's manufacturer, Verastem, is seeking full approval of the drug for CLL/SLL and accelerated approval for follicular lymphoma. Duvelisib is an orally administered dual inhibitor of PI3K-delta and -gamma, which are kinases involved in cell proliferation pathways. The FDA is expected to act by October 5, 2018.

Second CAR-T Cell Therapy Approved for DLBCL – Novartis announced that the US Food and Drug Administration (FDA) has approved its chimeric antigen receptor T-cell therapy (CAR-T therapy) called Kymriah for the treatment of relapsed/refractory diffuse large B-cell lymphoma (DLBCL) patients who are not eligible for an autologous stem cell transplant or who have relapsed following transplant. The approval follows findings from the Phase II JULIET trial, where Kymriah had an overall response rate of 50%, with 30% of patients experiencing a complete response and 18% receiving a partial response. Kymriah is a genetically engineered therapy that targets the CD19 antigen and is the second CAR-T therapy to be approved for DLBCL.

The author gratefully acknowledges the efforts of Grete Cooper, 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: SUMMER 2018

BY JACOB WEINTRAUB, MD

The 2018 IWMF Educational Forum was held in Chicago, May 18-20, and once more the Ed Forum proved to be a great event for learning about the latest in WM research, for bringing our questions to the WM experts, and for meeting and making friends, both old and new.

Meanwhile, discussions of all topics continue online. The posted links to articles of interest were sufficient to make an entire column, and many important topics were covered, including more discussion about the new, nonlive virus shingles vaccine, symptoms in WM patients with low IgM, and the new formulation of Imbruvica (ibrutinib).

HUMAN INTEREST/ARTICLES

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

One of Peter's links was to an article from CBS News about a three-time cancer survivor who finished the Boston Marathon, albeit 13 hours after starting. Peter voiced the hope that this article will give some of us encouragement to forge ahead, whatever the challenge and despite all odds.

<https://www.cbsnews.com/news/mary-shertenlieb-cancer-survivor-finishes-boston-marathon-13-hours-after-start/>

Peter also posted a link to an article titled "The Best Medicine? What's Meaningful to Our Patients." This article provides further evidence that sometimes it is important to let our medical staff know about special days or moments in our lives that are coming up, and that we would prefer, if at all possible, for the treatment regimen not to preclude us from being able to celebrate those special moments.

<https://www.nytimes.com/2018/05/03/well/live/doctor-patient-medicine-cancer-treatment-leukemia-meaning.html>

Peter then posted a link to an article from the Hastings Center, a bioethics research institute. The president emeritus, Daniel Callahan, discusses the opinion that palliative care and participation in clinical trials (or treatments) are not mutually exclusive. It is important that as many members of the IWMF as possible, including those participating in IWMF Connect, participate in clinical trials.

<https://www.thehastingscenter.org/palliative-care-vs-cancer-research/>

Wanda H also recently posted several links to items of interest, including a link to an article about the need for physicians to re-formulate their conversations with advanced cancer patients in light of all the new cancer treatments unfolding.

<https://nytimes.com/2018/04/19/opinion/sunday/problem-miracle-cancer-cures.html>

Another link from Wanda is to an article about an interview with a psychiatrist from the Dana-Farber Cancer Institute

about post-traumatic stress disorder (PTSD) in the context of someone who has been newly diagnosed with cancer or who has recently undergone treatment for cancer. This is an important consideration for all of us as we learn to cope with our diagnosis, both initially and as we go forward on our cancer journey.

<https://www.cancertodaymag.org/pages/spring2018/beyond-distress.aspx>

One last article from Wanda is about a topic that has been discussed repeatedly by the IWMF Connect group. With the title "Online Discussions Reveal Little-Known Side Effects," the article presents a technique called "deep learning" to analyze online conversations on the social network site **INSPIRE**. In the discussions about medical conditions (including cancer), the researchers found references to the skin in relation to side effects of treatment. Broader implications are discussed, too. Many of us have been participating in the Australian WhiMSICAL project to collect "big data." WhiMSICAL asks us to submit data including labs, treatment, and adverse effects, and has the potential to utilize the technique of "deep learning."

<https://www.cancertodaymag.org/Pages/cancer-talk/Patients-Online-Discussions-Reveal-Little-Known-Side-Effects.aspx>

Meg M also posted the link to an article about the high cost of cancer drugs. Treatment and medication costs are part of ongoing discussions online. Meg commented that we seem to have an excellent advocate at the FDA. The article posted is about the head of the Food and Drug Administration and the steps he is taking to increase the use of next generation sequencing for speeding up discovery of new treatments. The article also discusses the steps the agency is considering to keep cancer patients from "disproportionately" shouldering the cost of cancer treatments. To access this document, you must log in if you already have a Medscape account or register for a free account.

<https://www.medscape.com/viewarticle/895121>

LOW IGM AND SYMPTOMS

Cynthia N posted a question to the group. She was interested in learning if studies have been done on WM patients with low IgM, considering the various drugs now available and the frequently heard call to "treat the symptoms and not the numbers." Cynthia added that she was diagnosed in April 2001 when her IgM level was 2400. She has since been treated with Rituxan several times, and 2400 is her highest level of IgM to date.

Steve D posted that he thought there is a difference between those of us who, as in his own case, were accidentally

From IWMF Connect, cont. on page 19

diagnosed and were asymptomatic with low IgM (1000 for example) and others who have IgM that is quite low as the result of treatment.

Linda added that she has a low IgM at 780, but she has fatigue and has had it for six years. She has heard that Dr. Castillo has 20 patients with fatigue at a low IgM level. Linda's hemoglobin is normal. She is considering treatment but does not know if treatment will help her fatigue.

Michael T reported on his status as a member of the "low IgM group." At a relatively low IgM level, he was beset with strong symptoms including night sweats, significant weight loss, increased serum viscosity, and low hemoglobin. He was diagnosed in 2002 with IgM 20 Canadian scale (200 US scale). Over the years he has found that addressing his IgM before it gets too high shortens the treatment cycle and reduces the symptoms. He also has read on this forum that there are two "classes" of WM patients. One group has symptoms at a low IgM, and the other group does not experience symptoms until their IgM gets to a much higher level.

Judy K also added a comment about fatigue. She reports having an IgM of 300 with slightly low hemoglobin and extreme fatigue for at least five years. Her hemoglobin was 13 at last measure, but the fatigue has not changed. Her oncologist feels that the fatigue is not related to her WM, but her primary care physician has not found any reason for the fatigue. Understandably, this leaves Judy frustrated.

Dr. Jacob Weintraub, From IWMF Connect Editor, added a comment about fatigue. He posted that fatigue is common in people with cancer of all types. The topic has been discussed on IWMF Connect in the past as well. There is some thought of a multifactorial origin, while often there is no apparent cause for fatigue. Some people think fatigue is related to psychological issues such as depression that may not be clinically apparent otherwise. There is another suggestion that fatigue could be related to the increased metabolic burden that any cancer can impose on a person's body. Some measures that a person can take to counter fatigue include trying to increase exercise, being involved in counseling, practicing meditation, and other means. Sometimes, as noted, it just helps to know that there are others having the same problem.

Finally, Wanda posted a link to a video on fatigue on the IWMF website:

<https://lymphomanewstoday.com/2017/11/06/manage-cancer-related-fatigue-3/>

SHINGRIX VACCINE FOR SHINGLES

Coverage of this new vaccine was included in the previous column, and discussion continued online. Given the importance of the new vaccine, it seems appropriate to include the continuing discussion for the sake of general information and for those who missed it last time.

Wanda H posted a link to a *New York Times* editorial about the new vaccine. With the title "Why You Should Get the New Shingles Vaccine," the editorial is fairly inclusive and gives a history of shingles vaccines and a good description of what happens if a person gets shingles. It is written in straightforward language that is easy to understand. This article includes links to other articles including one about how cost effective the vaccine is and another with a summary of the Committee on Immunization Practices.

<https://www.nytimes.com/2018/04/09/well/why-you-should-get-the-new-shingles-vaccine.html>

Meg M added that she received the first Shingrix shot at a local pharmacy and did not need a prescription.

Karen R reported that, she, too, had received the first of the two shots at her doctor's office. She experienced some pain. She developed a major headache for two days and a low-grade fever at 99.3 degrees which was managed by Tylenol. The red spot at the site of the vaccine did not dissipate until after four days, and she still has a faint pink spot with a bruise.

Others, including **Meg M** and **Darwin E**, reported receiving the vaccine but only experiencing a sore arm for a few days. Meg added that it still is unknown how effective the vaccine will be for a person who is immunodeficient.

IMBRUVICA: NEW FORMULATION

Finally, there was considerable discussion about a press release from Pharmacyclics, the company that makes Imbruvica (ibrutinib), concerning its intention to introduce a new formulation of the drug. This announcement generated a flurry of posts and comments from WMers once the details of the new formulation were made clear.

Peter posted an excerpt from the press release stating that the FDA has approved a new tablet formulation of Imbruvica. Furthermore, the medication will no longer be available in capsules (specifically the 140 mg form). Imbruvica will be available only in tablet form.

Discussion ensued about the impact of the new formulation on the cost of ibrutinib, which appeared to be the same for all strengths of the new tablet. At this pricing, the cost will be about three times that of the original 140 mg capsule.

Gerri M reported that she received a call from her specialty pharmacy to inform her that her prescription for the new formulation of Imbruvica comes with a significant increase in her copay. Gerry, who has tolerated Imbruvica well for three years and has had an exceptionally good response, now found that not only will the monthly cost to be increased but the prescription quantity will also decrease from 30 to 28 days.

After some discussion about cost of the pills, **Dr. Tom Hoffmann** suggested that if the new 140 mg pill is going to

COOKS' HAPPY HOUR

BY PENNI WISNER

THE SAVORY AND THE SWEET

A few weeks ago, I made a wonderful dish I found in the *New York Times*: a Sri Lankan yellow dal with a topping of kale cooked with mustard seeds, onion, and coconut among other seasonings. The comments online were, well, wishy-washy; when I made the dal, I increased the spice and then decided the dish needed crunch. Peanuts? Chickpeas? I decided on chickpeas, probably because I love the ones from Nopalito (one of my favorite San Francisco restaurants) so much. Remember the ceviche recipe in a recent column? It was from *Nopalito, A Mexican Kitchen* cookbook. The book also inspired the fruit dessert part of this column.

I digress. The spicy chickpeas from Nopalito are fried—delicious, very crispy, not quite incendiary, but addictively spicy and salty. The internet to the rescue—recipes for roasted chickpeas galore. Here's what I have found: the chickpeas must be VERY dry in order to roast through and get evenly crispy, and a medium oven temperature works better too, allowing time for stirring which also helps get the crispy result so desired.

Drain two cans of organic chickpeas or cook an equivalent amount yourself. (Save the water, called aquafaba, and use it for vegan meringues or whatever treat you'd like to make for yourself. A trick is to chill the liquid before whipping; it cuts the whipping time in half.) I like Trader Joe's organic, canned chickpeas and find them not too salty and the liquid quite tasty. I sometimes use it to replace some of the oil in vinaigrette.

Spread the chickpeas on a rimmed baking sheet lined with a clean kitchen towel. Blot them with another towel and then leave them at room temperature to thoroughly dry. You could also put them in a low oven, maybe 150 degrees F, for an hour or so, stirring occasionally.

Once dry, transfer the chickpeas to a bowl and toss well with 1½ to 2 tablespoons canola oil, 1 heaping teaspoon ground cumin, 1½ teaspoons Kashmiri chile powder (or other hot chile powder; you might try smoked, hot, Spanish paprika), a pinch cayenne, and 1 teaspoon kosher salt or more to taste. All spices are, of course, to be adjusted to suit your taste; curry powder would be fun to try. Again spread the chickpeas on a rimmed baking sheet and roast in a 350 to 375 degree F oven, stirring about every 10 minutes, until evenly browned and crisp, about 40 minutes. Cool a little and then taste for salt and spice and adjust. Store in an airtight container and enjoy as a snack or on salads or dal or any dish that would benefit from a hit of spicy crunch.

Yikes! I have gone on and not gotten to the meat, whoops, the fruit, of the column. It will be fast, promise. Strawberries and raspberries should be popping at farmers markets when this column hits your mailbox. Take advantage of the season to make a terrific, quick, cool, summer dessert or snack: fruit popsicles. Start with 4 cups cleaned and stemmed berries, ¼ cup freshly squeezed orange juice, ½ cup agave nectar (or my favorite, Lyle's Golden Syrup), zest of ½ lime or lemon, and a pinch of kosher salt. Put all the ingredients in a blender and puree until smooth. Pour into ten popsicle molds and freeze until slushy. Set the popsicle sticks in the molds and freeze until set. You could also pour the mixture into ice cube trays and use the fruit cubes in iced tea, lemonade, or cocktails. Or you could make granité: pour the mixture into shallow pans and partially freeze. Use a fork to scrape the frozen surface up into flakes and return the pan to the freezer. Repeat several times. When ready to serve, scrape the mix into pretty, clear glasses as a refreshing dessert. Or, again, since it is cocktail season after all: spoon some of the granité into a cocktail glass and pour over 1½ ounces chilled tequila. Enjoy!

Our motto: Eat Well to Stay Well

World Lymphoma Awareness Day

September 15th is World Lymphoma Awareness Day. For more information and to learn how you can participate, visit the Lymphoma Coalition website www.lymphomacoalition.org

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note!

Contact information for all support groups is found on www.iwmf.com under GET SUPPORT. Details of support group meetings and other upcoming events are posted under NEWS & EVENTS. Please check there to confirm details of future events.

CALIFORNIA

Northern California

The Northern California Support Group met in June at the Kaiser Hospital in Vallejo, CA. Those members who were fortunate enough to attend the recent Ed Forum in Chicago shared all the latest developments they had heard about. After enjoying some pot luck yummy treats, the attendees shared an informative discussion about their personal experiences with WM.

COLORADO & WYOMING

In April, WMers in the Rocky Mountain area were treated to “a New WM Doc in Town.” The University of Colorado Cancer Center recently transferred from Weill Cornell a doctor who has specialized in WM, amyloidosis, and multiple myeloma. Dr. Peter Forsberg grew up in Denver and wanted to return to his home state. He was the featured WM speaker at a special luncheon breakout session within the Rocky Mountain Blood Cancer Conference, sponsored by the Leukemia & Lymphoma Society (LLS). There were various educational blood cancer sessions of interest throughout the day as well as lots of vendors, groups helpful to cancer patients, a free lunch, and a beautiful facility. Thirty-two WMers and caregivers attended the WM luncheon session with Dr. Forsberg. The group was delighted to have a new, local WM expert doctor. He was

lively, informative, interested; he will be a great addition to our already great local care. After his talk, Dr. Forsberg spent another 20 minutes answering questions from the group members. All told, there were about 300 participants at the day-long conference—patients with all types of blood cancers, caregivers, nurses, and others interested in these topics.

The local partnership with the LLS is a blessing to the support group which, while few in number, always turns out in force for this conference and the WM-specific breakout sessions. When not attending educational lectures, group members handed out IWMF materials to the newly diagnosed and to nurses, who were all interested in WM and in learning more about it. It was a fabulous day, very informative, good to connect with others in a similar situation, and particularly great to meet the new doctor specializing in WM.



*The banquet room group of WMers—
32 in attendance at our breakout for WM!*



*Char Seeman (WMer and patient of Dr. Forsberg), Dr. Peter Forsberg,
and George Koch, another WM patient who was new to our meetings*

FLORIDA

South Florida

Last October 2017, the group held its fall meeting at Memorial Hospital West in Pembroke Pines, FL. The first order of business was to discuss the WM-related activities of the support group leader, Charlie Koch, and all the other members. Then, a representative from the local chapter of the LLS advised us on available patient support financial programs. After watching the video of Dr. Treon's talk from the May 2017 IWMF Educational Forum, the meeting broke for a lunch provided by the LLS. After lunch, Dr. Daren Grosman, a hematology and oncology specialist at Memorial, answered both personal and general questions

Support Group News, cont. on page 23

about WM from those in attendance. During the meeting, the group presented Dr. Grosman and Elizabeth Marshall, the Memorial Hospital social worker who helps coordinate all the support group's local meetings and support activities, with personalized IWmf coffee mugs in appreciation for the outstanding service they both provide to the group. (The mugs had been ordered through the IWmf office earlier that year.) In February 2018, group members attended the one-day, free educational conference for patients, caregivers, and healthcare professionals (including lunch) at the Fort Lauderdale Marriot Harbor Beach Resort & Spa presented by the LLS. Dr. Steven Treon spoke at a special WM breakout session. The next group meeting is planned for July 23 with refreshments again provided by the LLS.



At the 2018 Ed Forum, members of the Chicago Support Group welcome Andrew Warden (Andrew stands at center; to his left is Don Brown, Chicago Area Support Group leader).

ILLINOIS

Chicago Area/SE Wisconsin

As a great finale to the wonderful record breaking 2018 Educational Forum, the Chicago Area Support Group had a diverse group of attendees at our meeting on Sunday, May 20. Many first-timers attended along with several support group leaders ranging from New Hampshire to Australia. Ryan Scofield and Don Brown shared their "stories of hope" relating to a younger person diagnosed in his 30s and an older person diagnosed at 59. Ryan is close to being a 10-year survivor while Don was diagnosed 16 years ago. Both shared stories involving multiple drug treatments and are currently feeling like they are at the "top of their game!" Don is a tennis player and Ryan is a hiker as well as being good WM friends. Ryan helps maintain their support group mailing list while Don and the program committee organize meetings.

We especially enjoyed the perspective of Andrew Warden, leader of the Australian WM support group, the WMozzies,

who attended the entire 2018 Ed Forum and then joined our Support Group afterwards. When our discussion topic became maintaining patient data and enabling patients to follow their blood test trends, Andrew had much to contribute, as he was responsible for helping establish WhiMSICAL as an IWmf-supported international patient database. Don emphasized the importance of tracking your key blood test numbers (hemoglobin and IgM) and watching trends and turning points as he shared a spreadsheet slide of his personal history.

Nine of the attendees stayed around to chat after the meeting which helped end a weekend of significant learning and meeting new patients and caregivers. We are looking forward to a summer picnic. Watch the website for the date and place.

See pages 26-27 of this issue for Andrew's report on the 2018 Ed Forum and his visit to Chicago.

INDIANA

In March, over 100 blood cancer patients and their support persons gathered in downtown Indianapolis for an "Evening with the Experts." Breakout sessions followed the main speakers. Dr. Steven Treon led the Waldenstrom's session; ten patients and their caregivers and family members attended. Dr. Treon opened with an overview of the physiology of WM and went on to discuss treatments, including some currently in clinical trials. In April, the group reconvened at the LLS office in Indianapolis for a presentation on "Healthy Living via Healthy Lifestyles." The speaker was a group member who was personally challenged to make changes in his lifestyle. He researched strategies and now lives his message; he shared what he has been doing to achieve his success. Nineteen patients and guests gathered for the presentation, group sharing, bagels, and coffee. To cap an active spring, 20 patients and support people met again in early June at the LLS office in Indianapolis. The speaker was Janell Faust, reiki master, yoga instructor, and herbalist. She presented information on common ailments and the potential cures available in the kitchen, refrigerator, and on pantry shelves. She discussed the benefits of yoga and the various kinds of yoga. She also demonstrated some stretches using chairs—attendees could remain seated and join in at the same time. The usual breakfast treats and coffee followed to fuel the much anticipated group sharing.

NEW YORK

Eastern NY/Western New England

After being AWOL for several months, group leader Mel Horowitz is making plans for an active support group calendar and looks forward to reconnecting to members. Mel thanks everyone who participated in the IWmf May 1 and 2 Giving Challenge of the Community Foundation of Sarasota County. Over \$55,000 was donated during that 24-hour

Support Group News, cont. on page 24

period, which means the IWMF qualified for the matching grant that tripled that amount! The first meeting of the year, in June, began with lunch followed by a speaker (and group co-leader) who attended the Chicago IWMF Educational Forum and reported on the most exciting and interesting news from the annual event.



Western New York Support Group meeting

Western New York

The Western New York Support Group met for lunch at the Macaroni Grill on May 24. We had our largest turnout yet, 16! Two attendees joined us for the first time as newly diagnosed. A few drove over an hour from the west and south to participate. We began our meeting sharing information gleaned from the 2018 IWMF Ed Forum. Lynn Milliman and her husband had returned from Chicago just a few days before so it was easy to share all the exciting and inspiring news from the Forum. We then followed our usual format of going around the table as each shared his or her experience with WM. One member is starting first line treatment with ibrutinib after 14 years of “watchful waiting.” A number of members in our group are being treated with ibrutinib, but this is the first time we heard from someone taking it as a first line. So far, he is doing well except for some bruising. Our newly diagnosed members were quite encouraged to meet and hear from fellow WMers who look and feel good after many years of coping with the disease. They left with a feeling of hope and a sincere appreciation knowing they are not alone. Hugs and kind words for one another abounded as we left, giving testament to the value of support groups. We’re planning our next meeting for the fall.

NORTHEAST KANSAS & NORTHWEST MISSOURI

Memphis

The Memphis area group continues to grow: in May 2018 members celebrated 12 years together. At the most recent

meeting, 11 attended, which is about average. One patient and spouse traveled nearly 300 miles to be there! Six members were able to attend the Educational Forum in Chicago and learned a great deal about WM. With half the year gone, the group has held two meetings, with two remaining. At the planned July 21 meeting, attendees are expected from Missouri and the Kentucky border, as well as the usual Tennessee and Arkansas patients. The final meeting of the year is planned for October 20. If you plan to be in the Memphis area, feel free to contact Bill Paul, group leader, for directions and join the gathering!

MICHIGAN

The next meeting of the Eastern Lower Michigan Support Group is planned for Saturday, August 11. Details are posted on www.iwmf.com under NEWS & EVENTS CALENDAR.

EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

An engaged group of twelve WMers met at a library in North Royalton, OH, for fellowship and support on a wintry Sunday afternoon in early April. Veteran patients and caregivers warmly reached out with resources, supportive guidance, and shared experiences to the new member who attended. In an open atmosphere, the discussion covered the gamut of WM and health care issues: second opinions, coordinating care between one’s local oncologist and a WM expert doctor, unnecessary treatment, maintenance Rituxan, and the trend toward impersonal patient experience as health care becomes more bureaucratic. A support group is an ideal vehicle for patients and caregivers to share their experiences, concerns, and hopes and can be a catalyst for change and empowerment. A tempting selection of wraps, snacks, desserts, and drinks certainly complemented the enjoyable afternoon.

SOUTH CAROLINA

The South Carolina Support Group met at the Hope Lodge (American Cancer Society) in Charleston on a Saturday in March. This was one of the largest meetings so far with 20 in attendance. One newly diagnosed member was very appreciative of the information and support he received at this meeting. In addition, two guests, a young man who was staying at Hope Lodge (while receiving treatment at the Medical University of South Carolina for another, very different type of rare blood disease) and his father, quietly sat in the back of the room and listened to members’ stories. At the end of the meeting, the father asked if he could say something. He shared their story and then said what a blessing it was for him and his son to have just happened to stop in at the meeting. He said the shared experience gave them hope and the realization that the son could live a very long and productive life despite his diagnosis and treatment. It was truly a “feel good” meeting for all in attendance.



Houston Support Group with Dr. Peggy Determeyer, in black, at the center

TEXAS

Houston

The Houston Support Group held its spring meeting in March at the home of support group leader Dr. Barbara (caregiver) and John Manoussos (WM) in Houston's Uptown-Galleria. The speaker was Dr. Peggy Determeyer, PhD, BCC, McGee Fellow in Bioethics and Aging at the Hope and Healing Center and Institute in Houston, TX. She spoke on "A Method for Engaging and Empowering the Public Regarding Aging and Health Care Issues, especially Cancer and Grief."



Houston Support Group members

She talked about the need for patients and their families to: *Speak up and ask questions of your doctors. *Read what papers you are signing in a doctor's office and, if not comfortable with them, do not sign, especially when research and treatment is concerned. *Understand your rights and options for treatment. Consent only when you have complete

understanding of all your options. *Bring another person with you as support on all visits to help sift through the medical information or to help make treatment decisions. *Explore options when faced with a chronic disease and seek a second opinion before treatment. *Understand the five stages of grief—denial, anger, bargaining, depression and acceptance—when confronted with an illness. Anger, denial, and bargaining (the first three), can come in any order.



Dr. Zachary Hunter, Lu Kleppinger, and her husband Tony Sabló

*Know that depression and other stages of grief are transient and normal, as is acceptance. The group enjoyed the hour-long program and interjected their experiences with WM throughout the talk. Light refreshments were served.

NORTHERN VIRGINIA / WASHINGTON DC / WESTERN MARYLAND

Dr. Zachary Hunter, PhD in pathology and director of genomics at the Bing Center for Waldenstrom's Macroglobulinemia, drew a crowd of over 60 WMers and caregivers in April for his presentation "Personalized Medicine in Waldenstrom's Macroglobulinemia: What It Means and How We Make It Happen." It was one of the largest groups in the four years since the reinvigoration of the IWMF support group in 2014. Dr. Hunter offered an up-to-the-minute report of findings in the Treon Laboratory explaining that research is now focused on personalized medicine, the specific needs of each individual. The goal is to determine, in advance of treatment, who will respond best to which treatments and who will have negative side effects, rather than treating solely based on symptoms and what diagnosis. To achieve this goal, Dr. Hunter described his research concentrating on the intricate inner workings of the human body at extremely microscopic levels. As director of genomics, Dr. Hunter was involved in a pivotal campaign to define the genomic landscape of WM. These efforts led to the

Support Group News, cont. on page 26

identification of the highly prevalent MYD88 L265P mutation found in over 90% of WM patients. Dr. Hunter's and Dr. Treon's findings were a key element that led to a clinical trial with ibrutinib and its subsequent fast-track approval by the US Food and Drug Administration. He also succeeded in identifying the first-ever reported somatic mutation in human cancer for CXCR4. Dr. Hunter discussed several treatments including ibrutinib as well as newer therapies such as venetoclax and ulocuplumab, with more to unfold in the coming months. A question Dr. Hunter is addressing is whether treatment regimens can limit their targeting to cancer cells and thus avoid damaging the DNA of healthy cells. Another major concept being investigated is tumor clone evolution: diversification and treatment.



A large attendance of over 60 participants attended Dr. Hunter's presentation at the Dewberry Life with Cancer Family Center in Fairfax, VA

INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

AUSTRALIA

New Australian WM Physician in IWWMF Directory

Associate Professor Dipti Talaulikar has been added to the IWWMF Directory of WM Physicians for Australia. She is a clinical haematologist at Canberra Hospital and has been principal investigator in clinical trials involving ibrutinib and BGB-3111 for Waldenstrom's patients.



Dr. Dipti Talaulikar

Meetings for WMozzies organised by Leukaemia Foundation of Australia

The Sydney WMozzies' meeting held on May 31 at Kirribilli Club, Lavender Bay, Sydney, was devoted to member WM experiences and situations and current WMozzies activities.

The National Blood Cancer Conference in Melbourne will be held on September 8 at the Melbourne Convention and Exhibition Centre with blood cancer plenary sessions. There will be WM streams with WM specialist speakers.



Peter Freese

WMozzies member joins IWWMF LIFELINE

Peter Freese is now on the IWWMF LIFELINE for patient support regarding Bing-Neel syndrome. The IWWMF was keen to have an additional and international patient join the Bing-Neel LIFELINE list for this rare syndrome.

IWWMF Educational Forum in Chicago

Andrew Warden represented Australia at the May 2018 Ed Forum. The many valuable highlights of the Forum are covered elsewhere in this *IWWMF Torch* issue. The following list highlights the opportunities at the Forum to promote the WhiMSICAL database:

- Assisting in a Forum one-hour breakout session on the Information Patient (iPatient) with Peter DeNardis to give an overview of WhiMSICAL;
- Having an information table for WhiMSICAL throughout the Forum, which enabled attendees to

International Scene, cont. on page 27



Roger Brown, UK, and Andrew Warden, Australia

receive promotional material and discuss personal points about WhiMSICAL;

- Meeting WMUK Chair Roger Brown and discussing the recent meeting in London between WMUK Rory Morrison Committee members and a WhiMSICAL principal investigator regarding current activities and potential future collaboration;
- Attending the presentation by Dr. Gwen Nichols, chief medical officer of the Leukemia & Lymphoma Society (LLS), that included plans and progress on the LLS initiative for a US registry. Dr. Nichols referred to the joint activities between LLS and WhiMSICAL specifically regarding patient-reported outcomes and a registry for non-US WM patients;
- Attending IWWMF support group leaders' meetings to discuss experiences and challenges as group leaders, as well as improvement opportunities;
- Attending a Chicago area support group meeting and experiencing first-hand the fellowship of IWWMF group meetings engendered by group leaders Don and Mary Brown. Fresh ideas were gained on support group organization and meetings;
- Meeting the international leaders from the new IWWMF affiliates in China, India, and Mexico and discussing new opportunities for their participation in WhiMSICAL.

Andrew Warden, WMozzies, reporting

CANADA

On April 25 the first Toronto Support Group was launched! Previously, the only support group in southern Ontario was in Oakville, about an hour east of Toronto. The Oakville Support Group was started by our dedicated WMFC President, Arlene Hinchcliffe, almost 20 years ago! Since then support groups have been started in Ottawa, Montreal, Calgary, Vancouver, and Halifax.

Forty patients, caregivers, family, and friends attended the Toronto meeting, which was held at Ellicsr Survivorship

Centre at the Toronto General Hospital. Dr. Christine Chen, a Canadian WM expert, spoke about "The Immunity System in WM." The slides are available on the WMFC website. Following this most informative presentation, patients, many of them newcomers, engaged in a round-table discussion and shared their stories about their WM journey.

We anticipate that the Toronto Support Group will provide an opportunity to reach out to more WM patients. We also look forward to greater collaboration between WMFC and local physicians. Our next Toronto meeting will be held on September 26. Check our website for further details: www.wmfc.ca

Also, please check the website for information on meeting dates and locations in your local area. If you do not have a support group near you, please contact us and let us know how we can help you start one!

Betty McPhee, WMFC, reporting

CHINA

I was astonished the moment I received the diagnostic report for my father showing that he had a blood cancer. I walked out of the hospital wondering how to tell him. The communication was hard, and I do not remember what I said to him. The local doctor told us that in our city she had only had three WM cases; most people had never heard of WM.

While my father was in treatment, I looked for useful information about WM, trying to understand it and its treatment. When searching online, I found some other WMers who had similar confusion, anxiety, and fear—they were seeking experienced doctors, good hospitals, and affordable medicine or therapy. They had many questions, such as why does my IgM remain high after treatment, will my father or



From left to right: Roger Yao, China, Elena Malunis, US, and Andrew Warden, Australia

mother die in three to five years, will my children have the same problem stemming from heredity, what kind of food and nutrition do I need? Especially with newly diagnosed WMers online, I could feel what a difficult time they were experiencing, the same as I had in the past few months.

Then I shared some factsheets and articles from the IWmf and other sources with other WMers and caregivers. They told me that they found these materials very helpful to understand the disease better. Apart from appreciating the reading materials, they also told me that they felt much more comfortable talking to other WMers rather than to friends or even family members. The comfort and encouragement during communication helped to release their stress and worries.

During the Chinese New Year holiday in February 2018, after discussion with some WMers and caregivers, we decided to establish our support group. We called it “WM-together.” The letters “WM” in Chinese stand for “we,” so “WM-together” also means “WE-together.”

Starting from a few members in our support group, we quickly attracted 50 members via social media. Most of them were caregivers because WMers, on average, are 65 years old, the “old generation,” and in China the “old generation” does not use computer and smart phones very often. Instead, most people joining our group are caregivers, the sons and daughters of WMers, with an average age of 30 to 40 years. To share popular scientific knowledge of WM, we set up an official WECHAT account which could regularly publish articles to our members via the social media app WECHAT. By the end of April our official account had more than 120 followers.

We collected education materials from the IWmf as well as other resources and translated some non-technical articles into Chinese so that our members could be updated on the latest WM news and information. We also developed a disease and treatment record template which helps members track all their information and treatment progress with ease and thus facilitate communication with their doctors.

Thanks to the convenience of online social media technology, our support members can communicate live with others via WECHAT. Whoever has questions can seek help and support in the group. This especially helps a lot of newly diagnosed WMers and their caregivers.

Our support group is very new, and we are exploring proper approaches to give better support to WMers in China.

Roger Yao, WM China, reporting

ITALY

A doctor-patient meeting, “Waldenstrom’s Macroglobulinemia: Living with a Rare Pathology,” was held at Niguarda Hospital in Milan on April 21. The meeting’s aim was to share with patients and caregivers the latest therapeutic approaches,

scientific developments, and testimonies of patients’ experiences in the fight against the disease. Special guest was Dr. Steven Treon of the Dana-Farber Cancer Institute in Boston, considered one of the world’s leading experts on the disease. What follows is an excerpt of the presentations.

Dr. Steven Treon

After thanking the medical team of the blood disease association directed by Dr. Enrica Morra, who significantly collaborated on research in fighting WM, Dr. Treon emphasized the role that patients have had in advancing the field. Patients allowed the researchers to carry out significant clinical studies and through their associations contributed to fundraising for clinical trials. Dr. Treon emphasized new and recently approved therapies and promising studies on drugs under investigation. He illustrated the recent monoclonal drugs that are overcoming the classic chemotherapeutic approaches and the study of the mechanisms related to the genetic mutations affecting WM patients.

Dr. Anna Maria Frustaci

Dr. Frustaci talked about approaches that can lead to an improvement in the quality of life of patients and of the fundamental role assumed by caregivers. In addition, she discussed the obstacles to progress due to the characteristic features of WM: the lack of availability of clinical data; the variety of symptoms and effects; the extremely variable clinical responses; and the different therapeutic approaches adopted by the various medical centers.

Dr. Alessandra Tedeschi

Dr. Tedeschi focused her presentation on the clinical therapies available today, and on how these have a significant influence on the various clinical and symptomatic aspects of the disease. She discussed the impact that the most recent drugs have had on the increase in patients’ life expectancies and highlighted the different therapeutic approaches in relation to different symptoms.

Dr. Beatrice Sofia Colombo

Dr. Colombo, a clinical psychology researcher, discussed the psychological problems facing WM patients, underlining how the fact that WM is an incurable disease has a considerable negative influence on the patients’ acceptance.

Patients participated in the meeting by asking the presenters lots of questions, especially related to hopes for improvements in quality of life offered by innovative drugs already on the market and in trial studies.

Ermanno Chiavaroli, WM Italy, reporting

UNITED KINGDOM

The trustees of WMUK decided to raise the organization’s level of support for the WM community in the UK. That

means providing more professional paid administration services, recruiting more trustees to spread the work, and increasing donated income to pay for future expansion of the registry and patient support. This also involves developing a new website from scratch, the existing website having got to the limit of what it could support.

The Rory Morrison Clinical Registry has now gained traction and has been fully certified to operate within the UK Health Service; it has 14 hospitals specializing in WM signed up and reporting full clinical data. By the end of the year, 700 patients should be on the registry, and those patients not currently treated at registry sites have been urged to ensure their data is included. This data must be available to support the 2020 re-evaluation of ibrutinib for long term funding in England. To assist, WMUK purchased an additional set of data-mining tools for the registry and is actively looking for funding post-2020, especially from pharma companies who seek a future pathway to UK reimbursement. Testing has been completed on the patient-entered data layer, which will automatically be requested from time to time by the system. With the registry now running smoothly, we have received overseas inquiries, and in principle we welcome these, so we can share the huge amount of work put into the registry construction.

Dr. Josh Bomsztyk, based at University College Hospital, London, our largest center, has been out and about briefing about the registry; he has also run a very successful WM session with Lymphoma Action at its Manchester conference. We hope to see more of this joint work. A poster presentation

for the British Society of Haematology annual meeting 2018 was successful.

Ibrutinib is becoming widely used in relapsed WM—over 130 patients are now being treated via the Cancer Drugs Fund. However, there is a new threat to limit availability. In chronic lymphocytic leukaemia (similar treatment patterns to WM), National Health Service England has put an arbitrary time restriction on ibrutinib use after relapse, to try and save money. If imposed on WM, it would be very serious in our indolent disease. All blood cancer charities and the parliamentary blood cancer group of which WMUK is a member are challenging this interference with the independence of The National Institute for Health and Care Excellence (NICE), whose decisions must normally be funded in full.

On the doctor front, a clinician group has been reconstituted to produce updated treatment guidelines to be supported by the British Society of Haematology. Our very popular guide to WM by Dr. Shirley D'Sa is also being updated to reflect changes in treatment options.

Finally, we shall welcome several potential trials in the autumn, including one for pembrolizumab (targeting PD-1 receptors, allowing the immune system to target cancer cells) run from Oxford by Dr. Jam Kothari, but with multiple UK centers. More information will be on our website in due course at www.wmuk.org.uk.

Roger Brown, chair of WMUK, reporting from 40,000 ft over Nuuk, Greenland, heading for the IWMF Ed Forum

START SPREADING THE NEWS!

THE 5TH INTERNATIONAL PATIENT & PHYSICIAN SUMMIT ON WM OCTOBER 13 and 14, NEW YORK CITY, NEW YORK

Autumn in New York! Take advantage of the season by making plans now to attend the **5th International Patient and Physician Summit on Waldenstrom's Macroglobulinemia** on October 13-14, 2018. The Summit will be held in the Financial Ballroom of the New York Marriott Downtown Hotel and Conference Center, located in lower Manhattan.

This will be a 2-day comprehensive conference on current topics of WM: genomics in the diagnosis and management of the disease, predispositions, disease presentations, clinical trial updates, case presentations, and much more! Selected speakers from the concurrent Workshop (10th International Workshop on WM) will chair and lecture the agenda presentations at the Summit.

There is **no fee** to register for the Summit, which is organized by the Bing Center for Waldenstrom's Macroglobulinemia, Dana-Farber Cancer Institute, in Boston, MA. However, because of space limitations, you must register in order to attend. Summit attendees are responsible for their own travel and hotel accommodations. A first-come limited room block has been secured at the New York Marriott Downtown Hotel for Summit attendees, and a link to the hotel is provided from the website below.

To be a part of it...go to <http://www.waldenstromsummit.org/index.php> for more information.

BETWEEN MARCH 1, 2018 AND MAY 31, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

<p>Barbara Aaron Malcolm and Ann Lander Angela Ritchie</p> <p>William A.S. Akana Margaret Akana</p> <p>Marvin Arenson Diane and Ivan Arenson</p> <p>Mark Biase The Ambruso Family Ann and David Bottomy Gail M. Breslin Willy and Dale Burgess Friends at IDSC Foundation Lee Ann Maximowicz John and Valerie Nickolenko</p> <p>Yoshiko Button John Button</p> <p>Galen Weare Clough Judith Fiddick</p> <p>Robert M. Coulbourn III Margaret Coulbourn Coscia Paul James Coscia</p> <p>John Eldridge Anonymous</p> <p>Fred Fischer Marlene Fischer</p> <p>John Flanzer Gloria Flanzer</p> <p>Denise Friedrich Donald and Susan Lanza Michael and Kammy Lanza</p> <p>Nancy Givens Charles Givens</p>	<p>Deanna Harrison Anonymous Susan Boling Riverheads Athletics Booster Club Riverheads High School Keith Stoddard Thomas Harrison Middle School</p> <p>Richard Holoff Susan Holoff</p> <p>Dr. Lisa Jane Krenzle Anonymous Carla De Landri and Florindo Volpacchio Eve Ellis and Annette Niemtzow David Gerson H. Steven and Deborah Graham Nancy and Bob Helfman Jacqueline Judd and Michael Shulman Carla Kozak Jeff and Krista Margolis Michael and Ann Margolis Elizabeth Mayhew Susan M. Meinerz Robert and Andrea Meislin Carol Moldaw Charles and Mary Jane Nash Marjorie Oberlander Ocko Solomon Family Louise Pesale Bruce and Yoke San Reynolds David Steinmann Annemarie Swingle</p>	<p>William Lyon Judith Lyon</p> <p>John Medovich Judith Barr Scott W. and Nancy M. Harris Rai and Tom Hutachinda Carol and Carl Lewis Linda Theiben Alan Toma Joni D. Urry Wilson</p> <p>John S. Myers Diana W. Myers</p> <p>Nancy O'Soro Anonymous David Baggs Ilenia Carrea James and Ellen Gard Terrance Hahn Nancy Heffron and Joyce Minasian Ashley and Marc Howard Richard and Cindy Humleker Kuberski Family Michael Kuzak Raymond and Jane Leather James and Melissa Taylor Thomson Elementary School Limor Weiner Mandy Wilds</p> <p>Robert Oster Lynn and Thomas Milliman</p> <p>Jo Ann Parrish Carmen McCormick</p> <p>Robert Rosencranz Anonymous</p>	<p>Robert Rosencranz (cont.) Barbara Brisky Nancy and Ken Grossman Group 11 Elliott and Marcia Lavey Fred and Teri Lowinger Goldie and Stephen Rayman Normandy Remodeling Champaign County Medical Society</p> <p>Herschel Shorr Gil Shorr</p> <p>Harvey Steinberg Martha and Arthur Brody</p> <p>Betty Jane Stoffa The Grimm Family</p> <p>Charles P. Vassallo Lucrezia Vassallo</p> <p>John Wasniewski Carla Wasniewski</p> <p>John E. "Jack" Wheeler Bryan and Mary Gosselin</p> <p>Norman David White Liz Guccione John and Anita Weier Georgia and Kevin Kiley Bruce White Cathy White Shirley White</p> <p>Marcia Wierda Michele and Matthew Bowling Robert and Marlene VanderVeen</p> <p>Nicholas Wyman Rebecca Ketchum</p>
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<p>Dr. Stephen Ansell Meg and Tom Mangin</p> <p>Gail Arcari Marjorie Marshall Gregory and Dee Ann Slover</p> <p>Arlene Arenson Diane and Ivan Arenson</p> <p>Sandi Lee Banks' Birthday Judie Blonder Doehrmann Janet Forney Mary Goldberg Michael Kaplan</p>	<p>Sandi Lee Banks' Birthday (cont.) Stacey Voynov and Jenny Olcovich</p> <p>Bruce Barron Edward Goldberg</p> <p>Jacki Barron Edward Goldberg</p> <p>Joan Bergland Joel Rosenblit</p>	<p>Rae Lynn Besaw's Birthday Jamie Defazio</p> <p>"Papa" Don Brown Jack Tieman</p> <p>Alexis Brynien Martin Brynien</p> <p>Dr. Jorge Castillo Donald and Alice Tracey Joseph and Carol Wielgus</p>	<p>Dr. Jorge Castillo and Dr. Steven Treon Ellen Hartline Ruth Lizotte</p> <p>Kathleen Coddington Jack C. Coddington</p> <p>Vincent Cole Chris Cole</p> <p>Caitlin Costello, MD Kathleen Battle</p>
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