



ISSUE 19.2

# IWMF TORCH

April 2018

INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

## INSIDE THIS ISSUE

In Celebration of  
Dr. Robert A. Kyle ..... 1

President's Corner ..... 6

Medical News  
Roundup ..... 7

IWMF Doc Star:  
Judith Trotman..... 10

Don and Kathryn  
Wolgemuth:  
The "Good Spirits"  
of Giving..... 12

IWMF Connect:  
Spring 2018..... 15

Cooks' Happy Hour ... 18

Support  
Group News ..... 18

International Scene.... 20

## IN CELEBRATION OF DR. ROBERT A. KYLE

BY MORIE A. GERTZ, MD, MACP



Dr. Kyle at his 90th birthday celebration, accompanied by  
Dr. Morie Gertz at Mayo Clinic Rochester, March 17, 2018

*On March 17, 2018, Dr. Robert A. Kyle celebrated his ninetieth birthday in Rochester, MN, where he has lived for 57 years with his wife, Charlene Kyle.*

*Dr. Kyle has been a strong supporter of the IWMF since its earliest days, most notably serving as chairman of the IWMF Scientific Advisory Committee from its inception until 2017, and, to this day, as a very active Trustee. Dr. Kyle is gratefully remembered by hundreds, perhaps by now thousands, of IWMF members who have approached him to seek advice or treatment recommendations at one of our annual Educational Forums or have heard him sharing his specialized wisdom from the podium at the "Ask the Doctor" event closing every Ed Forum. For a whole generation of Ed Forum goers, the Doctor is Bob Kyle.*

*The IWMF Torch, adding to the many good wishes occasioned by this birthday, presents here the talk delivered by Dr. Morie A. Gertz from the podium of the IWMF 2015 Ed Forum in honor of Robert A. Kyle. We are very pleased to share with our readers this remarkable tribute written, in his own inimitable style, by another hematologist who has known "RAK" for decades as mentor, colleague, and friend.*

*In Celebration, cont. on page 2*

# OFFICERS & TRUSTEES

## FOUNDER

Arnold Smokler

## PRESIDENT EMERITA

Judith May

## PRESIDENT

Carl Harrington

## SECRETARY-TREASURER

Beverly Docteur

## VICE PRESIDENTS

Elena Malunis

Michael Sesnowitz

Guy Sherwood, MD

## BOARD OF TRUSTEES

Stephen Ansell, MD

Peter DeNardis

Marlyn Friedlander

Sue Herms

Marcia Klepac

Robert A. Kyle, MD

Barry Nelson

Linda Nelson

Lisa Wise

## BUSINESS OFFICE

Jennifer Silva, Operations Manager

## IWMF SCIENTIFIC

### ADVISORY COMMITTEE

Stephen Ansell, MD, Chairman

Mayo Clinic

Bart Barlogie, MD

Mount Sinai Hospital

James R. Berenson, MD

Institute for Myeloma & Bone Cancer Research

Morton Coleman, MD

Weill Cornell Medical College

Meletios A. Dimopoulos, MD

School of Medicine,

University of Athens, Greece

Stanley Frankel, MD

Columbia University

Morie Gertz, MD

Mayo Clinic

Irene Ghobrial, MD

Dana-Farber Cancer Institute

Eva Kimby, MD

Karolinska Institute, Sweden

Robert A. Kyle, MD

Mayo Clinic

Véronique Leblond, MD

Hôpital Pitié Salpêtrière, France

Gwen Nichols, MD

Leukemia & Lymphoma Society

Roger Owen, MD

St. James's Institute of Oncology,

United Kingdom

Lisa Palomba, MD

Memorial Sloan Kettering Cancer Center

Surinder Sahota, PhD

University of Southampton, United Kingdom

Sheeba Thomas, MD

MD Anderson Cancer Center

Steven Treon, MD

Dana-Farber Cancer Institute

Brian Van Ness, PhD

University of Minnesota

*In Celebration, cont. from page 1*

Dr. Robert A. Kyle is known to all of you. He is an extensively published physician, and his numbers of publications are best expressed in scientific notation. He has nine first-authored articles in the *New England Journal of Medicine*, beginning in 1965 when he published the largest description of the hematologic effects of arsenic intoxication through his long-term study of prognosis in monoclonal gammopathy published in 2002. He coined the term "chronic idiopathic neutropenia," which is now referenced with his name. He was the first to recognize melphalan's ability to produce myelodysplasia and acute leukemia. He was the first to attempt to treat multiple myeloma bone disease to reduce the impact of skeletal complications. He coined the term "smoldering multiple myeloma" and "monoclonal gammopathy of undetermined significance." He also coined the term "idiopathic Bence Jones proteinuria." He was the first to perform prospective randomized studies in the treatment of amyloidosis, establishing the current standard of care for this disease. During his training his mentor, Ned Bayrd, asked him to review the electrophoretic patterns of patients in the newly opened electrophoresis laboratory at Mayo Clinic. Bob found that many of these patients had multiple myeloma and amyloidosis while a number of them had neither myeloma nor amyloid. He published this in *JAMA* in 1960. In 1960 Jan Waldenström coined and published in a Harvey lecture the term "benign monoclonal gammopathy." I think that to this day Bob kicks himself for not explicitly mentioning the presence of monoclonal proteins in the absence of symptomatic disease.

Bob performed the first syngeneic bone marrow transplant at the Mayo Clinic in 1964, a procedure undertaken long before anyone thought or heard of HLA antigens. The patient was a woman with aplastic anemia; she is now a 40-year survivor.

His first large review of multiple myeloma and amyloidosis appeared in 1961 in the *Archives of Internal Medicine* and was based on all patients

*In Celebration, cont. on page 3*



The *IWMF Torch* is a publication of:

International Waldenström's

Macroglobulinemia Foundation

6144 Clark Center Avenue • Sarasota, FL 34238

Telephone 941-927-4963 • Fax 941-927-4467

E-mail: [info@iwmf.com](mailto:info@iwmf.com) • Website: [iwmf.com](http://iwmf.com)

This publication is designed to provide information about the disease Waldenström's macroglobulinemia. It is distributed as a member service by the International Waldenström's Macroglobulinemia Foundation, Inc., to those who seek information on Waldenström's macroglobulinemia with the understanding that the Foundation is not engaged in rendering medical advice or other professional medical services.

#### EDITORS

Alice Riginos

Shirley Ganse

#### ASSOCIATE EDITOR

Sue Herms

#### SUPPORT GROUP NEWS

Penni Wisner

#### IWMF DOC STAR EDITOR

Ron Ternoway

#### IWMF CONNECT

Jacob Weintraub, MD

#### INTERNATIONAL CORRESPONDENT

Annette Aburdene

#### CULINARY EDITOR

Penni Wisner

#### CARTOONIST

Linda Pochmerski

#### PHOTOGRAPHY

John Kyle

#### FORMATTING & PRODUCTION

Sara McKinnie

#### TORCH ADVISORY PANEL

Carl Harrington,

Robert Kyle, Judith May,

Guy Sherwood

IWMF is a 501(c)(3) tax exempt non-profit organization Fed ID #54-1784426.

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

seen at Mayo Clinic with the diagnosis through that date. He has followed a cohort of 241 MGUS patients now for nearly 40 years. First bone marrow transplant at Mayo Clinic: 1963. First report on WM: *AJCP* 1965.

How did Bob become interested in hematology? At the time, part of the clinical training program required a choice among three possible avenues of laboratory pursuit. One was in cardiology, but this required that each of the residents undergo a cardiac catheterization, which he found less than appealing. The second was in the anatomic pathology laboratory, spending the day doing post-mortems. The third was working in the microscope laboratory, reviewing peripheral blood films and bone marrows, which appeared for all purposes to be the least onerous of the tasks.



*Dr. Kyle, who has a not-so-secret love of chocolate, chose this particular chocolate dessert which attracted a lot of attention from Trustee Sue Herms at an IWMF dinner.*

The International Waldenström's Macroglobulinemia Foundation awards the Robert A. Kyle Lifetime Achievement Award in his honor. The International Myeloma Foundation established a Robert A. Kyle Lifetime Achievement Award: he was the first recipient. He has received an Honorary Doctorate Degree of Medicine from Palacky University in the Czech Republic. He is a Master in the American College of Physicians, a recipient of the Mayo Clinic's Henry S. Plummer Distinguished Internist Award and Distinguished Mayo Clinician Award. He is a Member of the Royal Society of Pathologists in the United Kingdom. He became a Professor of Medicine in 1975 and a Professor of Laboratory Medicine in 1981. He is recipient of the Phillips award, the David A. Karnofsky Award and Lectureship from the American Society of Clinical Oncology, and the highest lectureship from the American Society of Hematology, the Wallace Coulter Award.

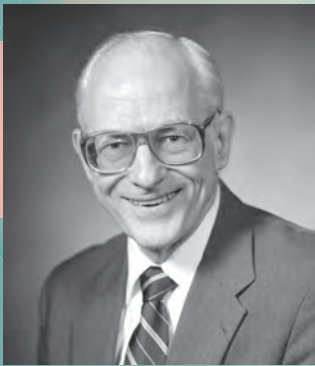
But let's talk a little bit about the man himself. Before "mentoring" entered the common parlance, Bob committed himself to the career development of Mayo Clinic junior staff including Drs. Rajkumar, Dispenzieri, Greipp, Kapoor, and Kumar. Before "mission, vision, and strategic planning" were considered vogue terms, he led and he taught by role modeling. During his patient-seeing years he was the last to leave the clinic every single evening. It was common knowledge that he would return from international trips, land at the Rochester airport at 9:00 pm, and then would come into the clinic to review correspondence, messages, and letters from patients, and complete letters to referring physicians. He saw phenomenal numbers of patients, always overloading his clinical calendar. When asked why he would burden himself so, his reply would be, "How would you feel if your mother or sister was requesting an evaluation and couldn't get one?"

Bob Kyle is a man who really knows how to kick back and relax. He doesn't dance, he doesn't sing, he doesn't play cards, but he knows how to dress down. On Saturday he wears a bow tie when he comes into work and indulges himself by reading *Sports Illustrated* in the car while his wife does the weekly grocery shopping. He has a legendary intellect. In the early 1970s at the dawn of the personal computer era, random access memory was referred to as having 16K, 32K. It was known that in our division the K stood for Kyle units. Before the advent of the electronic medical record, every serum protein electrophoresis that was performed at the Mayo Clinic was reported on a sheet of paper called the shingle sheet and each of the patterns had a K penciled on the sheet. I came to Mayo from Chicago, and, when I first saw the electrophoretic pattern with a K, I thought it was marked kosher. Subsequently, I was proven correct since any abnormal protein electrophoresis would mean a phone call from "Rabbi" Robert Kyle.



*Dr. Kyle and his wife Charlene near Promontory Point, Utah, 2017*





# *In Celebration of Dr. Robert A. Kyle*



*Dr. Kyle with his children Mary, Barb, and John in 1961.  
Daughter Jean arrived two years later.*



*Dr. Kyle with Dr. Jan Waldenström, circa 1994.*



*Machu Picchu, Peru 2012*



Easter Island 2017



Taj Mahal, India 2017



San Francisco 2017

### *In Celebration, cont. from page 3*

Bob not only was dedicated to his patients, he was beloved by them for his attention to detail. Many of his former patients continue to be seen at Mayo, if for no other reason than to inquire, “How is Dr. Kyle?”

Over the years he saved Mayo thousands of dollars by attending many, many lunch meetings and bringing his own lunch. Unfortunately, for me, it was the same lunch every day for 20 years – I watched him pull out bologna on dark bread with cheese whiz, a banana, and chocolate cake – no peaches, no grapes, no tangerines, no salami, no white bread – a banana every day for 40 years. He would eat his bologna sandwich, and you’d ask, “What’s up today?” And he would say, “Oh, I’m going to Prague” or “I’m going to Rio de Janeiro at 1:30.” And then he would finish his bologna.

At Mayo Clinic we have a Mayo Clinic Model of Care that is meant to set a standard for patient care. Before this model of care existed, Bob demonstrated what it meant to be a Mayo Clinic consultant, personifying what it is to be a healer and a comforter to the ill. Bob continues to educate, as he has now trained over 100 fellows who carry on his mission of compassionate and holistic care. He is a clinician, a researcher, an educator, a career counselor, a role model, and a father figure to scores of hematologists. Bob Kyle is a great man, but, moreover and more importantly, he is a good one and a kind one as well. And that makes him rare, indeed. In a profession where burnout, arrogance, and complacency with patients are constant threats, his enthusiasm and his inquisitiveness remain the same at 40 years as they were at 40 weeks. A famous quote of his is: “Every patient has something to teach you and every patient is unique.” A mantra of his that remains with me to this day.

Bob has witnessed a solar eclipse, was an elder of the Presbyterian Church, is an expert with maps. He is a legendary

philatelist (which, as most of you know, was legalized by the Supreme Court in June 2000), he sleeps blindfolded on an airplane, he is a renowned medical historian and photographer, and he has a photographic memory. He has bathed in the Antarctic; he was in the YMCA Indian Guides with his son. He is a man of integrity and a real mensch.

Bob Kyle was born in Bottineau, ND, where your head would fall into Canada if you had a syncopal event. For those of you who don’t know exactly where Bottineau is, it is in the center of a triangle of Dunseith, Gardena, and Souris, ND. I recently found that as a boy he tricked his brother, placing a firecracker in a can that led to a permanent scalp scar. So he has a bit of the devil in him, but not much.

I have a specific personal debt to Bob. If not for Bob, I would never have remained at Mayo and would now be practicing in Chicago...with an office off of Michigan Avenue...driving a Lexus...and living in a 7,000 square foot house... Thanks, Bob – ah – never mind.

For his goodness, for his ability to provide relief and solace to the ill and continue to fill them with hope, and for his career commitment to an incurable disorder, it is my great pleasure to present to you Professor Robert A. Kyle.<sup>1</sup>

<sup>1</sup> To learn more about Dr. Kyle’s remarkable career, see “Robert Arthur Kyle, MD: A Conversation with the Editor” by Robert A. Kyle, MD, and William Clifford Roberts, MD, in *Proceedings of the Baylor University Medical Center* 23.4 (2010): 400-418. Of special interest is the account on page 401 of the school system in Bottineau, ND. Bob Kyle’s education began at age 5 in a one-room school with 15-20 children in all eight grades taught by a single teacher. At age 12 he entered high school.



---

# PRESIDENT'S CORNER

BY CARL HARRINGTON

---

Did you ever notice that WM in IWMF is framed by IF?

As you progress through WM, you are surrounded by IFs starting with the initial, remorseful “if only” as in:

- *If only* I didn't have WM.
- *If only* I didn't have to worry about my kids getting WM. (By the way, most WMers don't really have to worry about that.)
- *If only* my disease were in control.
- *If only* I knew what to expect about the course of my disease.
- *If only* I knew what to expect about the side effects of treatment.

This stage of “iffy-ness” is usually followed by the more realistic “as if.” As in, “I have WM, but I'll live my life *as if* I still have a real future by:

- Taking the treatment with the smallest long-term side effects and the longest remission;
- Learning all I can about WM from the IWMF website and publications, from other WMers at support groups, and on LIFELINE, Facebook, and IWMF Connect...and, of course, from the *IWMF Torch*;
- Becoming my own best advocate when dealing with my doctor; and
- Getting a second opinion when I need treatment or retreatment.”



Eventually, the “as if” stage turns into the more hopeful “what if” stage where the questions become:

- *What if* everyone supported the IWMF? Each year, we are grateful to receive donations from 2000-2500 individuals. But we have 4-5 times that many people in our database. *What if* everyone gave?
- *What if* everyone got his or her friends and family to give too? Imagine what could happen if everyone got just five family members or friends to give to the IWMF! Can you make 2018 the year you come out and ask your friends and family to support the IWMF?
- *What if* we can “Imagine a Cure”?

Although we began as a support group in 1994, the IWMF was incorporated as a foundation in 1998. This fall will mark our 20<sup>th</sup> anniversary as a non-profit corporation!

In those 20 short years we've made enormous progress. In 1998 we had four treatment options. Now we have over 30, and that list is growing rapidly. And even better, the treatments yield longer, deeper remissions with fewer side effects. And in the same time span, life expectancy has grown from “who knows?” to 3-5 years, to 6-8 years by 2010, to the 16-20 years that Dr. Treon talks about today.

We are getting closer than ever to a cure. In fact, “Closer Than Ever” is the theme of the 2018 IWMF Educational Forum in Rosemont, IL, May 18-20, at the Westin O'Hare Hotel. I hope to see you there.

Our goal at the IWMF is to stop being plagued by “IFs” and pack them into LIFE. Let's focus all of our energy on our IWMF vision of “supporting everyone affected by WM while we advance the search for a cure.” In short, we want to change the status from “if” we can get a cure to “when” we get a cure. If we all work together, we can make that happen.

Stay well,

Carl

## Have Your Say

The *Torch* welcomes letters, articles, or suggestions for articles. If you have something you'd like to share with your fellow WMers, please contact *IWMF Torch* editor Shirley Ganse at [shirleyganse@hotmail.com](mailto:shirleyganse@hotmail.com)

---

# MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

---

## **Changes to Ibrutinib (Imbruvica) Formulation Announced**

– The US Food and Drug Administration has approved a new formulation of ibrutinib (Imbruvica), and all US patients who use the drug will require new prescriptions. Rather than the existing 70 mg and 140 mg capsules, the new formulation will be in tablet form and available in different strengths of 140 mg, 280 mg, 420 mg, and 560 mg. This means that patients may now take one pill, once daily, no matter their dosage. For example, a patient currently being prescribed 420 mg daily will now take one 420 mg tablet daily instead of three 140 mg capsules. The tablets will come in a 28-day blister pack. The tablets are becoming available now, and the original capsules will no longer be available in the US after May 15, 2018.

## **Combination of Ibrutinib and Rituximab Demonstrates Improvement in Progression-Free Survival in Phase III Trial for WM**

– AbbVie announced interim results from the iNNOVATE Phase III clinical trial evaluating ibrutinib (Imbruvica) in combination with rituximab (Rituxan) in 150 patients with treatment-naïve and previously-treated WM. The trial successfully met its primary endpoint and demonstrated improvement in progression-free survival compared to rituximab alone. All trial participants received IV rituximab once weekly for four weeks, followed three months later by a second rituximab course once weekly for four weeks. They were randomized to receive either ibrutinib at 420 mg or a placebo once daily until criteria for permanent discontinuation were met. Secondary objectives of the trial, which is still ongoing but no longer recruiting participants, include overall response rate, hematological improvement measured by hemoglobin, time-to-next treatment, overall survival, and number of adverse events.

## **Phase II Trial Reports Results of Ofatumumab in WM**

– A multi-center US Phase II trial, reported in *Lancet*, looked at once-weekly ofatumumab (Arzerra) in 37 untreated or relapsed WM patients. For cycle one, patients received one of two dosing regimens: Group A (15 patients) received 300 mg during week one followed by 1000 mg during weeks two-four, and Group B (22 patients) received 300 mg during week one followed by 2000 mg during weeks two-five. Patients in both groups with stable disease or a minor response after 16 weeks were eligible to receive a re-dosing cycle of 300 mg during week one and 2000 mg during weeks two-five. Patients responding to cycle one or the re-dosing cycle who then developed disease progression within 36 months could receive cycle two of 300 mg during week one and 2000 mg during weeks two-five. All 37 patients were included in the efficacy and safety analyses. After cycle one, 51% achieved a response, which increased to 59% after the re-dosing cycle. Of the 13 patients who received cycle two, 77% achieved a

response. The most common serious adverse effects were infusion reactions at 11%, chest pain at 5%, hemolysis (red blood cell destruction) at 5%, and neutropenia (low number of neutrophils) at 5%. IgM flare was experienced by two patients, both in Group B.

## **Researchers Perform Retrospective Analysis of Infections Associated with Ibrutinib Use**

– An article in the *European Journal of Haematology* written by researchers at Vanderbilt University Medical Center reported on a systematic review of the incidence and types of infections associated with ibrutinib (Imbruvica) use in patients with hematologic malignancies. This retrospective analysis looked at published studies of ibrutinib and noted that infectious complications were common, occurring in 56% of patients taking single-agent ibrutinib and in 52% of patients on ibrutinib combination therapy. Approximately one in five patients developed pneumonia, which was the major contributor to a 2% rate of death from infections. Many of the observed pneumonia infections were due to opportunistic pathogens such as *Pneumocystis*, *Histoplasma*, *Cryptococcus*, *Nocardia*, and *Aspergillus* species. Other than pneumonia, infectious diseases included sepsis (a life-threatening response of tissues and organs to infection), urinary tract infection, upper or lower respiratory tract infections, sinusitis, cellulitis, and febrile neutropenia (low number of neutrophils accompanied by fever). The researchers observed grade 3 to 4 (severe to life threatening) infection rates of 20-26%, which is similar to those observed in trials of traditional cytotoxic regimens, and suggest that this side effect profile warrants careful consideration in selecting patients for ibrutinib therapy.

## **WM Patients Excluded from Further Enrollment in Phase I Study of BGB-3111 Combined with Anti-PD-1 Antibody**

– A study presented during the American Society of Hematology (ASH) Annual Meeting in December discussed Phase Ib data for the use of the BTK inhibitor BGB-3111 (zanubrutinib) combined with the anti-PD-1 antibody BGB-A317 (tislelizumab) in patients with previously treated B-cell malignancies. The data were presented by BeiGene, Ltd., which is developing both drugs. Initially this study enrolled 13 patients with indolent lymphoma (including two WM patients) and 12 patients with aggressive lymphoma. The WM patients developed autoimmune hemolysis, which occurs when antibodies attack and destroy one's own red blood cells. This resulted in the decision to exclude further enrollment of WM patients in the trial. BGB-3111 is a BTK inhibitor in the same class as ibrutinib (Imbruvica), and BGB-A317 is a humanized monoclonal antibody that belongs to the class of agents known as immune checkpoint inhibitors.

*Medical News Roundup, cont. on page 8*

**IRAK4 Kinase Inhibitor to Be Tested in Phase I Clinical Trial** – Curis, Inc. announced initiation of a Phase I clinical trial of CA-4948, an oral small molecule inhibitor of IRAK4 kinase, for the treatment of patients with relapsed/refractory non-Hodgkin's lymphoma. The first stage of the study will establish the maximum tolerated dose, with the expansion stage to focus on specific populations of patients with lymphomas harboring alterations in the MYD88 gene or Toll-like receptor (TLR) signaling pathway. IRAK4 has been validated as a target in diffuse large B-cell lymphoma and WM. The clinical trial identifier on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT03328078.

**New Phase II Study Opens for TGR-1202 in Relapsed/Refractory WM and Marginal Zone Lymphoma** – TG Therapeutics, Inc. is recruiting patients for a Phase II study of TGR-1202 (umbralisib) in patients with relapsed/refractory WM and marginal zone lymphoma. TGR-1202 is an oral PI3K delta inhibitor, in the same class as idelalisib; however, unlike idelalisib, it has not been associated with treatment-related pneumonitis, colitis, elevated liver enzymes, *Pneumocystis* infection, or cytomegalovirus (CMV) reactivation. The trial anticipates enrollment of 40 patients and will be conducted at Lombardi Comprehensive Cancer Center in Washington DC. The clinical trial identifier on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT03364231.

**More Information Released on Safety and Efficacy of New Shingles Vaccine** – GlaxoSmithKline released additional information regarding the safety and efficacy of its new shingles vaccine, Shingrix, in immunocompromised patients. Shingrix recently received approval from the US Food and Drug Administration and from Health Canada and is awaiting the issuance of vaccination guidelines from the US Centers for Disease Control (CDC). Regulatory reviews are currently underway in the European Union, Australia, and Japan. This new Phase III data looked at Shingrix use in 1,846 adult patients who had received autologous bone marrow stem cell transplants. In transplant patients aged 50 and above, the efficacy of the vaccine to prevent shingles was 67.34%; in patients who did develop shingles, the vaccine reduced the incidence of post-herpetic neuralgia, a type of chronic nerve pain that can remain after shingles treatment. No safety issues related to the vaccine were detected during the study. Shingrix is the first shingles vaccine to use a non-live antigen and is combined with a substance called an adjuvant to generate a strong and sustained immune response. It is given in two doses, from two to six months apart. Previously, the only available shingles vaccine was a live virus vaccine not indicated for those with weakened immune systems, such as leukemia and lymphoma patients.

**Ibrutinib and Venetoclax Combination Shows Early Promise in Relapsed/Refractory CLL** – The combination of ibrutinib (Imbruvica) and venetoclax (Venclexta) is

showing early promise in the treatment of relapsed/refractory chronic lymphocytic leukemia (CLL) patients. Interim results from the CLARITY study were presented during the American Society of Hematology (ASH) Annual Meeting in December by the Leeds Institute of Cancer and Pathology in the United Kingdom. Fifty patients were enrolled and treated with two months of ibrutinib; at two months, venetoclax was added with weekly dose escalations. The primary endpoint is eradication of minimal residual disease (MRD) in the bone marrow after 12 months of treatment with the combination, with the possibility of stopping therapy rather than indefinite treatment. After six months of treatment with the combination, approximately one-third of patients were MRD negative. There was one case of tumor lysis syndrome, which is a group of metabolic abnormalities that can occur when large amounts of tumor cells are killed off at the same time by treatment, releasing their contents into the bloodstream. Other adverse events included 33 patients with bruising and 25 patients with severe neutropenia (low number of neutrophils).

**Trial Compares Venetoclax/Rituximab to Bendamustine/Rituximab in CLL** – AbbVie released results from the Phase III MURANO clinical trial comparing venetoclax (Venclexta) in combination with rituximab (Rituxan) to bendamustine and rituximab in patients with relapsed or refractory chronic lymphocytic leukemia (CLL). Progression-free survival at two years was estimated at 84.9% for venetoclax/rituximab treatment versus 36.3% for bendamustine/rituximab. The trial enrolled 389 patients, 194 of whom received venetoclax/rituximab. The dose of venetoclax was ramped up from 20 to 400 mg daily to mitigate tumor lysis syndrome, and beginning at week six, rituximab was given by IV monthly for six 28-day cycles. Patients continued with venetoclax at 400 mg for a maximum of two years or until disease progression. The primary adverse effect in both arms was neutropenia (low number of neutrophils), and it was greater in the venetoclax/rituximab arm.

**New T-Cell Immunotherapy for NHL and CLL Gains Investigational New Drug Status** – Eureka Therapeutics, Inc. announced that the US Food and Drug Administration has allowed Investigational New Drug status and authorization for a Phase I clinical trial of ET190L1-ARTEMIS T-cell immunotherapy for the treatment of relapsed and refractory CD19+ non-Hodgkin's lymphoma and chronic lymphocytic leukemia. In pre-clinical studies, this treatment matched the cancer-killing potency of current CAR T-cell immunotherapies but with a significant reduction in the levels of inflammatory cytokines that are typically released and can lead to toxic side effects. The trial began on January 15 of this year and is located at Duke University Medical Center in Durham, NC. A small group of patients will be tested first to establish the maximum tolerated dose, with expansion of the



trial to follow. The clinical trial identifier number on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) is NCT03379493.

### **Verastem Plans to Submit Duvelisib to FDA for Approvals**

– Based on data from two clinical trials, Verastem is submitting its oral PI3K inhibitor duvelisib to the US Food and Drug Administration for full approval for the treatment of relapsed/refractory chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) and for accelerated approval for the treatment of relapsed/refractory follicular lymphoma. Duvelisib is in the same class as idelalisib. In the study of CLL/SLL, the overall response rate was 73.8%, while the overall response rate in the study of indolent non-Hodgkin's lymphoma was 46%. Duvelisib in both studies was administered at 25 mg twice daily. The most common adverse events included neutropenia (low number of neutrophils), anemia, thrombocytopenia (low number of platelets), and diarrhea.

### **Older Lymphoma Patients Should Not Be Excluded from Autologous Stem Cell Transplant Based Only on Age**

– According to a retrospective study of 107 patients aged 70 and older performed by Dana-Farber Cancer Center and Massachusetts General Hospital and published in *The Oncologist*, older lymphoma patients should not be excluded from treatment with autologous stem cell transplant therapy based only on their age. The research team studied the medical records of patients who had autologous stem cell transplants at these institutions from 2000-2016. Sixty-five percent were alive at two years after transplant, while 58% did not experience disease progression. Looking at potential factors that determined success or risk, the researchers noted that patients who were in their first complete remission while undergoing transplant lived longer without disease progression compared to those who had a transplant during active disease. Those in their second or later complete remission had poorer outcomes than those in their first remission. Risk scores, age, and the year of treatment did not impact progression-free survival times, and the researchers found no factors that impacted overall survival.

### **FDA Issues Warning That Biotin Supplements May Interfere with Blood Test Results**

– Biotin supplements have gained popularity with those seeking stronger hair, skin, and nails, but the US Food and Drug Administration recently warned that taking biotin supplements can alter results in a wide range of medical tests, including those for anemia, cancer, heart disease, pregnancy, and thyroid problems. The reason for this warning is that biotin is used in medical tests to bond with blood proteins that are measured to detect many health conditions. The results of these tests may be skewed

by patients taking biotin supplements. It has been suggested that healthcare providers alert patients to temporarily stop taking their biotin supplements before getting blood work, although there is uncertainty about how much time is needed to clear biotin from the blood.

### **Phase II Trial Looks at R-CyBorD Therapy in Low Grade Lymphoma**

– A report in *Leukemia & Lymphoma* from Mayo Clinic researchers discussed results of a Phase II clinical trial of the combination rituximab, cyclophosphamide, bortezomib, and dexamethasone (R-CyBorD) in relapsed low grade and mantle cell lymphoma. The trial included 21 patients, five of whom had WM/LPL. The regimen consisted of rituximab (Rituxan) on day 1 with weekly cyclophosphamide, dexamethasone, and bortezomib (Velcade) in a 28-day cycle. Bortezomib was administered intravenously at 1.3 mg/m<sup>2</sup>. Low blood counts and peripheral sensory neuropathy were the most common adverse events. With a median follow-up of 38.1 months, the response rate for WM/LPL was 80%. Median progression-free survival and overall survival for all patients were 11.6 months and 54.8 months, respectively. The authors suggest that subcutaneous administration of bortezomib is likely to be even safer and that R-CyBorD may be a reasonable treatment option for patients who relapse after receiving two or more lines of therapy.

### **Phase I Study Reports Results of New Drug Selinexor for Multiple Myeloma and WM**

– A Phase I dose escalation study of selinexor alone and in combination with dexamethasone was reported in the journal *Blood* and included 84 patients, 81 of whom had relapsed/refractory multiple myeloma and three of whom had relapsed/refractory WM. Selinexor is an oral drug that inhibits nuclear transport of the XPO1 protein, thereby promoting the accumulation of proteins inside the cancer cell nucleus and inducing cell death. Overall, 25% of patients achieved a response, while those patients who received twice weekly selinexor at 45 mg/m<sup>2</sup> plus dexamethasone achieved an overall response rate of 50%. The most common adverse effects were nausea, fatigue, loss of appetite, vomiting, weight loss, and diarrhea, and the most severe adverse event reported was thrombocytopenia (low number of platelets).

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



## IWMF DOC STAR: JUDITH TROTMAN

EDITED BY RON TERNOWAY



*Dr. Judith Trotman speaking at the "Bloody Great Night Out" event*

Dr. Judith Trotman is a clinician and researcher with particular expertise in lymphoma care in Sydney, Australia. She has built a broad portfolio of clinical trials across the spectrum of lymphoid malignancies, including the INNOVATE (ibrutinib plus rituximab) and the BGB-3111 trials for Waldenstrom's macroglobulinemia (WM) patients.

When she was 13 years old, Judith was victim of a serious motor vehicle accident in her hometown of Wellington, New Zealand. She lay unconscious, one tube in each lung, on life-support, in intensive care at Wellington Hospital. As her parents sat worried at her side, a very self-important physician introduced himself as being "from Chest and Administration" and gravely declared that Judith's situation was very uncertain. To which her quick-witted mother brusquely asked "was that because of the Chest or the Administration?"

Judith spent a month in the hospital recovering from her injuries and drew from the experience two lessons that led her to a career in medicine: the importance of laughter in our lives and the need for respectful, empathetic interactions with patients.

One of five children, Judith had a conventional 70s' childhood. "I worked pretty hard around the house, played sports, joined Girl Guides, went to Sunday mass. The weekly highlight was watching TV for two hours on a Sunday night. We were expected to study hard and be mindful of others less fortunate." Her father's daily mantra was "Try your best and be nice to someone who hasn't got many friends."

Her father had fled the coal mines of Newcastle-Upon-Tyne by ship at the age of 16 for a new life in New Zealand, where he met Judith's future mother while working at IBM.

After enduring the embarrassing family stories that her college teacher – her mother – told in her physics class at St. Mary's College in Wellington, Judith completed her medical training in New Zealand, then moved to Sydney, Australia, with the intention of specializing in the treatment of Human Immunodeficiency Virus (HIV) patients. Twenty years on, she is director of the Hematology Clinical Research Unit at Concord Repatriation General Hospital (CRGH) in Sydney.

She met her husband, Stephen, in Sydney – a widower with three children, including twin boys. They are parents to three boys of their own, including a second set of twins. In addition to a full-time job with a multinational Australian insurance company, Stephen is a more-than-equal partner in all aspects of family life. "The deal for all Stephen's indefatigable support at home is that we had to stay in Tamarama (a surf beach next to Bondi beach)."

Dr. Trotman worked in 2009 and 2010 at the Clinical Research Unit in Hôpital Lyon-Sud, France, the Lymphoma Study Association, along with LYSA, the world-leading French lymphoma trials collaborative. Her own research, demonstrating the predictive power of PET-CT response assessment after first-line therapy in follicular lymphoma (FL), has informed National Comprehensive Cancer Network (NCCN) guidelines and recently led to PET scans being publicly funded for FL patients in Australia.

She is co-inventor of ClinTrial Refer, a free mobile app that provides instant knowledge of the eligibility criteria for currently recruiting cancer clinical trials in Australia. There are now 22 different versions of ClinTrial Refer, and Dr. Trotman has received government funding for a ClinTrial Refer Australia app, putting all clinical trials across all disciplines in Australia into the pockets of physicians and patients.

Dr. Trotman is also principal investigator for the WhiMSICAL project to collect "big data" from WM patients globally. She presented a poster at the 2017 Annual Meeting of the American Society of Hematology summarizing the findings from nearly 300 WhiMSICAL participants.

For the past ten years she has played a leading role in raising funds for the Concord Cancer Centre, Sydney. This year's fundraising event entitled *A Bloody Great Night Out!* entertained more than 600 supporters decked out in black or hemoglobin red and raised over \$155,000 to fund two additional nurses for clinical trials. As a result, many more blood cancer patients will now have access to new treatments not otherwise available in Australia.

*IWMF Doc Star, cont. on page 11*





The Concord Cancer Centre Haematologists at "A Bloody Great Night Out!" event wearing "hemoglobin red"; Dr. Judith Trotman, second from right

"CRGH is not in a wealthy area, but my colleagues and I are supported by our patient community," she says. *"A Bloody Great Night Out!"* raises money for our clinical trials research, but most importantly builds community. It is an opportunity for patients to party with their clinicians."

Andrew Warden, leader of Australian WM support group WMozzies, WhiMSICAL co-investigator, and one of Dr. Trotman's patients in the INNOVATE clinical trial, summarizes her contributions: "Judith is a driven, inspirational professional who is passionate about helping patients, whether it be patient education, patient care, fundraising, or research."

In the past five years Dr. Trotman has twice chaired the organizing committee for WM patient conferences featuring presentations from leading European WM specialists and hosted another patient meeting at which IWMF President Emerita Judith May and her husband spoke.

And what about that mythical work-life balance? "I don't have it, but I'm pretty comfortable with the constant juggle of too much of everything!" Her formula for professional success as a woman in a field in which men continue to hold most of the senior leadership and academic roles? "Wit and grit!"

When asked the question "What do you think will have the biggest influence on hematology in the next ten years?" Dr. Trotman's response echoes the lesson she learned as a 13-year-old:

"Patients – finally the medical community is listening to them! I mean really listening and starting to focus on the research that meets their priorities. There is a strong development of the science behind the collection and analysis of patient recorded outcomes, and of patient preference research. In lymphoma research, our most common primary endpoint, progression free survival, fails to capture the totality of the patient experience."

And what advice does this energetic, empathetic clinician, researcher, and mother of six impart to newly-diagnosed Waldenstrom's patients?

"First, I validate their experience. Fatigue, poor concentration, and neuropathy are concrete and disabling symptoms, and it's important for patients to be able to describe just how that impacts their lives.

"Secondly, I tell them there is an energized global community of doctors, patients, and scientists working together to minimize the impact of WM on patients' lives, with huge advances in well-being and survival, in the past decade in particular.

"I tell them my goal is that a newly-diagnosed patient of mine will live long and live well – a life defined by things other than having WM."

Note: Those wishing to participate in WhiMSICAL may sign up at [www.cart-wheel.org](http://www.cart-wheel.org)  
See also [iwmf.com/news-and-events/news/global-patient-database-wm](http://iwmf.com/news-and-events/news/global-patient-database-wm)

---

# DON AND KATHRYN WOLGEMUTH: THE “GOOD SPIRITS” OF GIVING

BY MITCH ORFUSS

---

In the German language, the word “wolgemuth” – pronounced *wall-guh-mooth* – means “good spirits.” If you had the opportunity to meet and talk with Don Wolgemuth, you would quickly come to see that his name describes him perfectly! Don is an 82-year-old resident of Lancaster, PA, currently living in a retirement community with his wife Kathryn. They have had a long, happy life of farming, firewood, and great generosity – perhaps unique in the annals of the IWWMF – for Don has supported IWWMF with donations in each of the last 20 years. His story is both interesting and typical of the journey to and through WM for many patients.

In 1993, Don began to develop symptoms of vertigo, so he did some scouting and quickly found his way to a specialist in vertigo who practiced in nearby Philadelphia. The blood work taken at that first visit showed elevated IgM, and the specialist suggested that Don see a hematologist-oncologist to explore why. Don found one fairly near his farm in Lancaster. The doctor suggested watching and waiting, monitored by quarterly blood work to keep assessing the changing situation.

Don’s numbers slowly deteriorated until his physician suggested in 1997 that it was time to take the next step and do a bone marrow biopsy. The nurse called afterward to tell Don that he had Waldenstrom’s macroglobulinemia. Even those two unpronounceable words themselves were, as Don related, quite alarming! Clearing his head, Don decided to call a cancer hotline. The staff there evidently knew what they were doing: they quickly referred Don to none other than Arnie Smokler, who had begun a support group for WM patients. What luck! Don and Kathryn called Arnie, who was a tremendous help.

As Don related, “My wife and I had a winter house in Florida then, and we were invited by Arnie to visit him in person. Arnie oriented me to what was known about Waldenstrom’s in those days of the WM Support Group (WMSG). I went back to my local Lancaster oncologist to discuss what to do next, and I started on fludarabine, one of the few treatments for WM at the time. Unfortunately, it did not work very well for me. Feeling confused and worried, I went back to Arnie for his advice. Arnie told me that he would join me by traveling from his home in Florida to visit Dr. Stanley Frankel in Baltimore, which is not far from our farm. Dr. Frankel was one of the very few doctors in the late 1990s with any kind of reputation for knowing and dealing with Waldenstrom’s. We went to Baltimore. I told Dr. Frankel that my local oncologist wanted me to continue on fludarabine. That was not working well, so I was not eager to continue.”

Don continued on his journey: “So Dr. Frankel told me about a new treatment that had a lot of promise. It was called Rituxan. That sounded worth trying, so with Dr. Frankel’s guidance I was accepted into a clinical trial in 2001. As time went on, Rituxan started working for me, and soon Dr. Frankel was referring to me as a poster boy for Rituxan! That made me feel good. Soon after, though, Dr. Frankel took a new job in New York, and being a country boy, I decided not to follow him. And then my luck turned again. I learned about the Hershey Medical Center from others attending our wonderful local WM support group, by now part of the relatively new International Waldenstrom’s Macroglobulinemia Foundation. I started seeing Dr. James Ballard there...and soon, he retired! What a roller coaster! I started wondering what I might have been doing to drive these fine doctors away from me!

I was referred to another terrific doctor there, Dr. Giampaolo Talamo, who started me on bendamustine and Rituxan. I found the bendamustine hard to tolerate. I continued on Rituxan for many years. Then in 2013 I developed a big lump under my left arm, accompanied by night sweats and weight loss. Dr. Talamo suggested I try Velcade, which I did in 2014, and it really brought my IgM down. You will not be surprised to hear that I also developed some neuropathy. By then it was getting harder for me to commute to my medical appointments, and so Dr. Talamo kindly arranged for me to transfer my care to Dr. Samuel Kerr right down the road from us in Lancaster. Now the commute was shorter and easier for me.”

In 2015 under Dr. Kerr’s care, Don started on ibrutinib. “It was effective for about two years,” he relates, “but then my IgM started to rise again and so in late 2017, just a few months ago, I had four rounds of Rituxan and my IgM started to go in the right direction. We decided that I would continue only Rituxan on a quarterly maintenance basis. And that brings us to today. I am 82 and very active. I was still chopping trees for firewood on our farm until the farm became too big for us, and we moved to a wonderful retirement community. We are very happy here. I still exercise every day. No symptoms, no weight loss. I am doing well and am truly amazed I am still here feeling good after 20 years. And...I did not even tell you I was diagnosed with prostate cancer in 2000, had the surgery, and have had no problem since!”

Don and his wife have been incredibly generous to IWWMF over the last 20 years, not once missing a year of donating to the Foundation. That’s a tremendous commitment. Moreover, in 2017 Don and Kathryn created the Donald and Kathryn Wolgemuth Research Fund of the IWWMF.

*Don and Kathryn Wolgemuth, cont. on page 13*

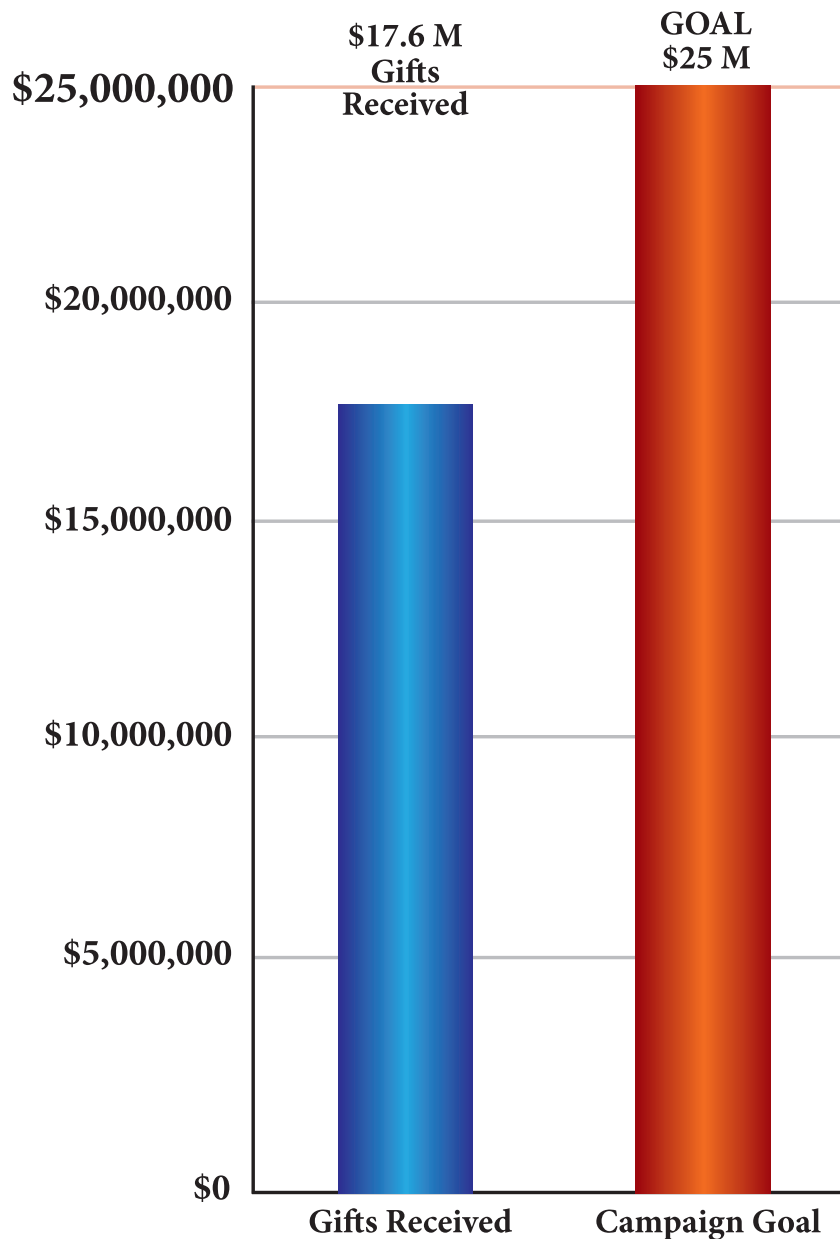


“The IWMF, starting with my earliest contact with the great Arnie Smokler, is a wonderful organization,” Don says. “I really appreciate the *IWMF Torch*. Kathryn has been dealing with her own disease – Parkinson’s – so our traveling days are largely over. She is doing pretty well with meds that help her symptoms, her own terrific support group, and the help of a great neurologist. We have the resources to keep donating every single year to the IWMF. It is so important that the organization continues to be in a position to help all WM patients, as it helped me starting way back in 1997, but strong member participation is necessary to keep the activities funded.

We are very grateful to be here as healthy as we are. I feel we could not have done it without the support of the IWMF.”

Gifts like those from the Wolgemuths have enabled the IWMF to provide support to WMers throughout the world and fund cutting-edge research that has led to better treatments and brought us closer to a cure. Last year roughly one fourth of our members collectively donated over \$2.5 million to the IWMF, allowing us to continue our important work, and we thank each and every one of them for their support. Just imagine what we could accomplish if everyone contributed annually!

### Imagine a Cure Campaign Progress Report as of February 28, 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

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 [dave@dbenson.com](mailto:dave@dbenson.com)



---

# IWMF CONNECT: SPRING 2018

BY JACOB WEINTRAUB, MD

---

Now that winter is behind us and the weather is warming up, we start to think about the spring IWMF Educational Forum, where we will hear about the latest in treatment and research, meet old friends, and make new ones. IWMF Connect continues in all seasons with topics old and new as new issues arise and new members join and ask questions about topics that have been discussed before.

## HUMAN INTEREST ARTICLES AND VIDEOS

IWMF Connect Manager and IWMF Trustee **Peter DeNardis** posted several links of general interest. One link was to an article written by a stage IV lung cancer patient and published in the journal *The Oncologist*. He explains his way of defining hope and living his life according to that definition. Many of his sentiments resonated with Peter and are feelings we deal with on a regular basis in this group.

<http://theoncologist.alphamedpress.org/content/22/12/1535>

Another link was to a very moving video of former US Vice President Joe Biden offering comfort to the daughter of US Senator John McCain during an interview (Biden's son died from glioblastoma, the same cancer that McCain is dealing with).

<https://youtube/3Sa8G-VR13Q>

Finally, Peter posted a link to an article titled "What to Say When You Meet the Angel of Death at a Party" from the *New York Times* on January 26, 2018. This author beautifully pens what many of us experience when others learn of our diagnosis.

<https://mobile.nytimes.com/2018/01/26/opinion/sunday/cancer-what-to-say.html?referer>

**Wanda H** posted a link to a historical look at cancer treatment using Babe Ruth as a backdrop. This is an interesting perspective in comparison to today's practices. I think we really don't appreciate how our current treatment modalities have improved compared to what was done in the past. The article is titled "No One Told Babe Ruth He Had Cancer, but His Death Changed the Way We Fight It."

<https://www.popsoci.com/babe-ruth-cancer-treatment>

Wanda also shared a link to an article titled "Seriously? Finding the Lighter Side of Cancer," which suggests that making jokes and appreciating humor has never been more important than after a diagnosis of cancer.

<http://www.curetoday.com/community/mike-verano/2016/07/seriously--finding-the-lighter-side-of-cancer?p=2>

One more posting by Wanda was a link to an article titled "'Adulthood' Through Cancer: A Step-by-Step Guide." Although this is written by a mantle cell lymphoma survivor, the lessons he has learned in his journey are applicable to all of us.

<https://www.curetoday.com/community/kevin-berry/2018/01/adulthood-through-cancer-a-step-by-step-guide>

Finally, **Scott W** posted a link to an interesting article titled "From Mouse to Monkey to Humans: The Story of Rituximab." Many of us have heard this story of how rituximab (Rituxan) came to be, but this is a nice review. It is very informative to many who are just coming into the WM community and are faced with treatment choices.

<https://speakingofresearch.com/2009/07/13/from-mouse-to-monkey-to-humans-the-story-of-rituximab/>

## PLASMAPHERESIS

Plasmapheresis (PP) is a procedure not used frequently now but in the past was a mainstay of treatment. Periodically, discussion arises with respect to the procedure itself and its effectiveness.

**Cal** asked about plasmapheresis without the use of such things as a permacath or PICC line. Cal will be in need of PP soon and has only a subdermal "smartport." He asked if anyone has had PP via arm veins, if there are any special considerations for using arm veins, and if this is done in the hospital or a clinic.

**Dr. Jacob Weintraub** added clarification that PP is the process of circulating blood through an instrument that removes the plasma (with excess IgM) from the blood and reinfuses the blood with "new" plasma added. It can be done weekly, monthly, or at other intervals, depending on the rise in IgM and serum viscosity. It reduces viscosity until chemo can be used to treat the WM or to prevent an IgM flare that can occur at the start of some treatments, especially Rituxan.

**Megan D** answered that her husband Mark had PP done multiple times using just his veins. He had over 30 PPs and did very well.

**Phil P** answered that when he had PP, they used one arm vein out and another vein in. At the time he learned that it is rare not to have a PICC line for PP, but the tech said he had great veins, so he proceeded. He suggested talking with the PP tech for an opinion.

**Meg M** reported that she had PP twice at Mayo Clinic in Rochester, MN. She doesn't have good veins, but each time the staff were able (with some difficulty) to access antecubital veins, though she only has one antecubital vein that can accommodate the large needle required. The PP nurses suggested a Hickman port after the first PP, but Dr. Ansell said it wasn't necessary since PP would be only a short-term strategy for her.

*IWMF Connect, cont. on page 16*

**Mark D** added that he had to have PP a few times when he was initially diagnosed. A Hickman port was placed in a neck vein, but it turned out to be very difficult because the port was painful and it leaked. He had good veins at the time and feels that it might have been better to use them.

**Fay L** added that she has received many, many PPs using needles in her arms. She thinks this is the less desirable way today. She was not eligible for a PICC line, so that was not an option; she has had an external catheter for many PPs. However, she was not told about all the maintenance that an external catheter needed daily and weekly. Also, care needed to be taken to be sure the catheter did not get wet; otherwise it was not a problem and PP went more quickly through the catheter. She always had PP done in a hospital or blood center. Fay added that PP usually reduced her IgM by about one half. In her case, her IgM returned to pre-PP level in three weeks, so generally it is considered only a temporary measure.

## PLEURAL EFFUSION

Pleural effusion is a condition of fluid accumulation in the pleural space around the lungs that is not seen commonly but has been reported by a significant number of IWMF Connect members.

**Louisa J** reported that her husband is taking ibrutinib. He just had a thoracentesis, and 500 mL of fluid was drained from his chest by needle aspiration. He is breathing much better but is feeling tired and sore. He had been taking ibrutinib as part of a trial, and his IgM, RBCs, and IgA are all much improved and stable. He did have a small amount of fluid found on a CT scan at the start of the trial. Louisa was trying to figure out why the fluid buildup occurred despite the positive treatment response.

**John P** reported that he had a pleural effusion before starting ibrutinib. The fluid resolved when he started treatment but returned when ibrutinib was stopped. He restarted treatment. His oncologist mentioned a low/no fat diet to help reduce the fluid buildup, but he has not tried this. He has heard about a permanent tap that could be placed to prevent further fluid accumulation.

**Peter S** commented that he developed pleural effusions after ending an 18-month trial with ixazomib-dexamethasone-Rituxan. Over two months he had fluid drained eight times. He is now in a venetoclax trial, and the effusions have lessened to a negligible level. He has heard about a semi-permanent tap, but it has some downsides.

**Dr. Tom Hoffmann** added some medical information from his perspective as a cardiovascular and chest surgeon who has treated many pleural effusions. Usually the effusions are handled in a stepwise fashion, starting with intermittent needle aspirations, as have occurred with Louisa's husband. These can be done by a pulmonologist or radiologist. In a person with WM, successful treatment of the WM usually will stop the fluid buildup, but this may be a slow process. If

WM treatment and intermittent drainage fail, more invasive procedures may be needed, such as a pleurodesis, but this is not common in WM patients. *[Editor's note: pleurodesis is a procedure that causes the membranes around the lungs to stick together and prevents the buildup of fluid in the space between the membranes.]*

Finally, **Angela B** reported that her husband had to have a pleurodesis, and it was the right choice, stopping the fluid buildup without recurrence.

## SHINGLES VACCINE

Vaccines are often discussed on IWMF Connect. One very relevant issue is the use of live vaccines, especially the vaccine to prevent shingles that, until now, has been contraindicated for immunocompromised patients. However, a new non-live vaccine called Shingrix has been approved by the FDA. This was noted in the January 2018 *IWMF Torch* Medical News Roundup by Sue Herms, IWMF Trustee and Research Committee Member. The discussion on IWMF Connect took place after the January *IWMF Torch* (issue 19.1) was released. It is worth repeating the discussion and information, since the issue affects so many of us.

**Louisa M** asked if it is worth having the new non-live shingles vaccine if a person already has had shingles. She is keen to do whatever she can to prevent a recurrence of her shingles.

**Bill B** commented after this, and another discussion followed, this time of facial paralysis (Bell's palsy) and shingles. Bill noted that WM patients should be able to take the new shingles vaccine even though we are immunocompromised. He has had severe facial paralysis, called Ramsey Hunt syndrome, which involves shingles in the ear. This might have been avoided if the new vaccine had been available.

**Penny J** asked if the new vaccine is available. She had received the old live Zostavax vaccine when it first came out, prior to her diagnosis of WM. She had no problem with the vaccine but still got shingles this year. However, it was a mild case, likely due to her receiving the vaccine. She definitely will get the new vaccine when it is available.

**Dr. Tom Hoffmann** added that guidelines for the new vaccine have been issued from the Advisory Committee on Immunization Practices of the Centers for Disease Control (CDC). *[Editor's note: This committee is recommending that all immunocompetent adults over age 50 get vaccinated with Shingrix, including people who have had shingles or who have had the old Zostavax vaccine. The guidelines have not yet addressed the use of the new vaccine for immunocompromised patients. Although Shingrix is preferred, Zostavax can still be used for healthy adults 60 years and older to prevent shingles, especially in certain cases, such as when a person prefers Zostavax or is allergic to Shingrix.]* Finally, **Wanda H** posted a link to information about the new vaccine. This

information is made available by the Chronic Lymphocytic Leukemia (CLL) Society.

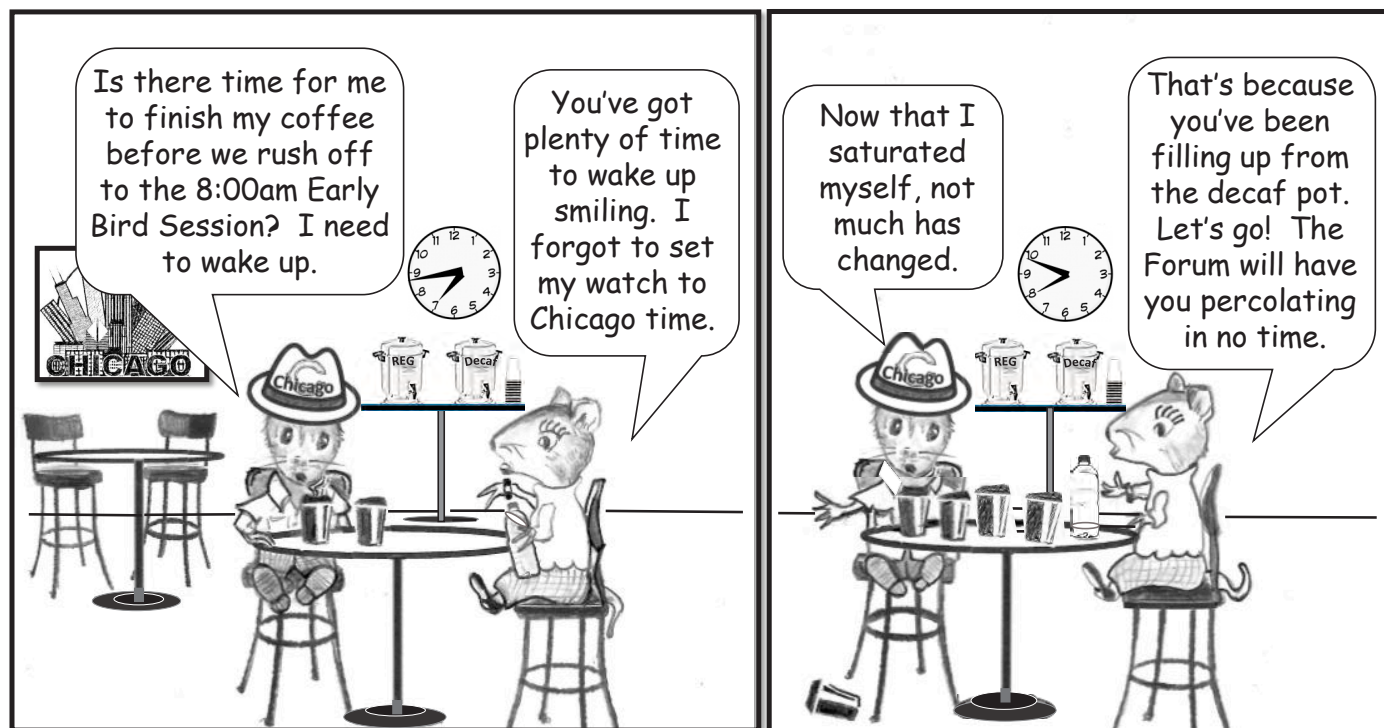
<https://cllsociety.org/2017/11/shingles-vaccine-cll/>

\*\*\*\*\*

As always, the discussions here represent only a small portion of the wide range of topics discussed and the postings to

general and more scientific articles. You are all invited to join and just “lurk and listen” or participate. The group has a great wealth of information and is more than willing to offer support and suggestions about many different subjects. If you have any discussion topics that you are particularly interested in, please let me know and I will try to include those discussions in a future column. I wish you all continued good health in 2018.

### *Winnie and Wally at the IWMF Educational Forum by Linda Pochmerski*



*Wally will awaken with smiles when he joins with Winnie, fellow patients, and caregivers at the opening "Early Bird Session." He'll also want to hold onto his new hat—the rest of the Ed Forum's agenda will blow him away.*



**It Will Be a Whirlwind, Wonderful, & Welcoming  
WM Weekend in the Windy City - Come Out  
& Connect at the 2018 Ed Forum!**

The Chicago area will host the IWMF Educational Forum on May 18-20 at the Westin O'Hare Hotel in Rosemont, IL, near Chicago O'Hare Airport. Everything you need to know to register for the Ed Forum and reserve your hotel room is located in one easy place on the IWMF website at: <https://www.iwmf.com/news-and-events/iwmf-educational-forum>.

**Don't miss it - see you there!**



---

# COOKS' HAPPY HOUR

BY PENNI WISNER

---

I want to share a cooking trick with you. But here's the thing: I might have told you about it before. The list of contents from past columns contains no clues. Maybe you don't remember either. And maybe this time, you will try the idea. It sounds crazy, but it works. Maybe a scientist among our readership can explain how. Intrigued?

Easter and springtime both have strong associations with eggs. And eggs form a classic combination with another springtime treat, asparagus. Specifically, a soft-boiled egg with a runny yolk sits atop a pile of steamed asparagus glistening with butter. And maybe a sprinkling of truffle salt. Oh boy, now that would be a treat! (I am writing just before dinner.) But how do you peel an egg with a soft yolk? Ah ha! This is what I am here to tell you about.

Steam the eggs. Yes, steam them. Put your steamer basket in a pan with one inch of water. Put on the lid and bring the water to a boil. Add your eggs. They can even be refrigerator cold. Only one has cracked so far and I have been using this technique for a year. Set your timer and steam the eggs for five or six minutes. You will have to experiment to find the timing that works best for you. When done, plunge the eggs into water. It does not need to be cold, room temperature would be fine. This stops the cooking. Now, dry the eggs and carefully roll them on a countertop to crack the shells all over. Look for the air bubble at one end and start peeling there. The

shell comes off miraculously easily, leaving a smooth surface of unblemished white.

If you want warm eggs on warm asparagus, the vegetable should be cooking at the same time as the eggs. Toss the asparagus with a little butter or olive oil and season with salt and pepper. Cut the eggs into halves or quarters and arrange them on top of the asparagus. Drizzle with a little more olive oil or melted butter and add a sprinkling of salt and pepper. Recently I discovered toasted black sesame seeds with salt. They would make an attractive garnish. You might also try my new favorite, nutritional yeast; it is particularly delicious on popcorn. If you don't add butter or oil, and you season your popcorn with salt and the yeast, it fairly well qualifies as a healthy treat. Especially when paired with sparkling wine.

If you are busy being trendy and making avocado toast, these soft-yolked eggs are the ticket to top the avocado. But note that the Southern California fires this year devastated many orchards, which has made the fruits more expensive; more will need to be imported from Mexico. On warm days, you could also make yourself a salad nicoise with line-caught tuna packed in olive oil, black olives, capers, minced red onion or shallot, boiled potatoes, quartered eggs, fresh lemon juice, olive oil, and salt and pepper.

*Our motto: Eat Well to Stay Well*

---

## SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

---

### **Please note!**

Contact information for all support groups is found on [www.iwmf.com](http://www.iwmf.com) under GET SUPPORT. Details of support group meetings and other upcoming events are posted under EVENTS. Please check there to confirm details of future events.

### **CALIFORNIA**

#### *Monterey Bay Area*

A very small group of WMers and family gathered in early January. More had planned to attend but colds and flu kept the group small. Without a formal agenda, the group had plenty of time to visit and share. One long-time member drove from Monterey; he had lots of wisdom to share. Since so many were sick, a big topic of conversation was strategies for staying healthy: getting lots of rest, avoiding stress, and especially paying attention to handwashing – the

most important thing to do to stay healthy. Every time one returns home from anywhere, the first stop should be the sink to wash the hands. And, of course, always wash them before eating. Suzie Shook, group leader, found a great video by the Centers for Disease Control and Prevention (CDC) with handwashing tips: [www.cdc.gov/handwashing/index.html](http://www.cdc.gov/handwashing/index.html). The next meeting is planned for Sunday, April 8, at the Sutter Maternity and Surgery Center from 1:30 to 3:30 pm.

### **CONNECTICUT**

Gail Arcari sent a note to announce that she is leaving her position as support group leader. "It is with great regret that I resign from being a support group leader. I have learned so much. I found my present oncologist through the group and I treasure all the wonderful friendships. It has been a real privilege and honor to help. However, I have developed

*Support Group News, cont. on page 19*

aggressive diffuse large B-cell lymphoma and am undergoing treatment, so I am leaving the group in very good hands. Bob Hammond has shared the leadership role with me for 12 years and Bob Ulkus joined the team as a leader in 2016. Good health to you all and blessings.”

### INDIANA

The Indiana WM support group has expressed interest in supportive lifestyle approaches to manage WM. One of the group’s members, David Chance, will be talking about “Healthy Living via Healthy Life Styles” at the Saturday, April 21, meeting. It will take place at the Indiana Leukemia & Lymphoma Society, 9075 North Meridian Street, Suite 150, Indianapolis, from 10 am to noon. There will be time as well for sharing, questions, and just catching up. Coffee and breakfast snacks will be available.

### EASTERN OHIO, WESTERN PENNSYLVANIA, AND WEST VIRGINIA

In spite of the cold and occasional snow flurries, a large and enthusiastic group of WMers gathered at the Hilton Garden Inn in Akron, OH, for a mid-November meeting. During the delicious lunch of salad, sandwiches, and an array of dessert choices, folks took advantage of the opportunity to catch up with old friends and meet new members. Following lunch, attention turned to the featured speaker, Dr. Paolo Caimi, a hematologist and oncologist affiliated with University Hospitals Cleveland Medical Center. Dr. Caimi presented an insightful overview of lymphoma and then focused on the unique characteristics of WM with a history of treatment options, including promising new therapies, such as venetoclax. Members especially appreciated his sincere interest in addressing their burning questions on a wide range of topics. Some stayed following the presentation to mingle, and others felt the need to head home because of unpredictable weather conditions. The group plans to meet in early spring 2018 to celebrate the end of winter with renewed hope as advances in WM continue to roll in.

### NEW YORK

#### *New York Metro Area*

A higher than usual turnout of about 30 members of the New York Metro Support Group met on January 28 at Weill-Cornell Medical Center’s beautiful Mahon Patient Resource Center. It was a wide-spectrum meeting during which the group bid farewell to, and shared remembrances of, a wonderful group member recently lost to amyloidosis – a rare complication of Waldenstrom’s – and welcomed two newly diagnosed patients who were attending their first meeting and seeking equilibrium following their recent unexpected diagnoses. The NY group stepped up helpfully and enthusiastically with all sorts of sound orientation advice, and it was heartening for all to see the newbies emerge from the meeting two hours



*Dr. Ed Libby, Dr. Steven Treon, and Dr. B. Jane Distad  
at Seattle Symposium, January 2018.*

later feeling a sense of relief (not to overstate it!) and more confidence to start taking charge of their disease going forward. Everyone was naturally reminded about why the support groups have profound meaning, and the importance of attending: not only to get support, but to give it.

### WASHINGTON

On January 13 almost 100 Washington State Support Group members attended a WM symposium in Seattle, headlined by Dr. Steven Treon of the Bing Center, Dana-Farber Cancer Institute. His main talk, “Genomic and Treatment Advances in WM,” captured everyone’s attention in the morning. Dr. Andrew Cowan, oncologist at the Seattle Cancer Care Alliance (SCCA), discussed Waldenstrom’s 101, and Dr. Jane Distad, neurologist at University of Washington, covered peripheral neuropathy and its causes and effects. This complicated subject encouraged questions since it affects everyone so differently. After a box lunch, Kate Ueland, nutritionist at SCCA, gave an engaging and informative talk. The meeting ended with the always popular “Ask the Doctor” session during which Dr. Treon presented three case studies. For each one, attendees had to decide what treatments to give and why, based on four, five, or six options. It was a fun eye-opener, and attendees learned a lot about drug approaches, the choices doctors have to make, and the difficulty of making these decisions. It also reinforced the saying, “When you’ve met one WMer, you’ve met one WMer.” Dr. Treon’s appearance in Seattle was supported by the Bing Center, IWmf, and SCCA. Dr. Edward Libby, oncologist at SCCA, facilitated the symposium. Videos and PowerPoint slides of the presentations are available on SCCA’s website at: <https://www.seattlecca.org/donate-and-volunteer/past-patient-education-events>.

---

# INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

---

## CANADA

The WMFC is pleased to be hosting our first one-day educational forum in Halifax, Nova Scotia, on Saturday, October 27, 2018. Guest speakers will include Dr. Zachary Hunter of the Dana-Farber Cancer Institute and Harvard University and Dr. Shirley D'Sa of University College London Hospitals. Please have a look at the Waldenström's Macroglobulinemia Foundation of Canada's website at [www.wmfc.ca](http://www.wmfc.ca) for more details on upcoming events.

WMFC has a new support group in Toronto, Ontario! The group will host its first meeting on Wednesday, April 25, at 6:30 pm, with guest speaker Dr. Christine Chen, University Health Network, Toronto.

**Arlene Hinchcliffe, President of WMFC, reporting.**

## UNITED KINGDOM

Following the approval of ibrutinib for relapsed patients last October in England, WMUK has been busy rolling out Rory Morrison Registry hospital sites throughout the UK. This is funded by Janssen UK and WMUK.

Although the prime objective is to capture ibrutinib patient treatment data with a central doctor-run hub at University College London Hospitals, it also aims (subject to continued funding) to capture retrospective and new data on all other patients. This is hugely ambitious for our small charity. At present over 70 new patients are already benefiting from ibrutinib.

With new treatments in the pipeline, usefully flagged by the IWMF, the Registry should prove a very valuable pathway for those pharma companies aiming to get their WM products funded for our National Health Service. Patients themselves have been very active in applying gentle pressure on consultants not yet involved, asking why their data is not being captured. There has also been overseas interest in the Registry, which we want to be as open and collaborative as possible.

However, with one step forward with ibrutinib we have potentially one step back, as bendamustine + rituximab treatment is now threatened. It is widely used, very cost effective, particularly as a first line treatment, but as it is used "off label" in our National Health Service (NHS), it is assessed in a different and competitive way against all other medicines. It is proposed that future funding be withdrawn at the end of this year – those already on it will continue – and so we have been lobbying and campaigning to reverse the decision. There is also another potentially bad outcome for a proposal to add bortezomib back into the treatment list for WM. NHS funding for bortezomib was discontinued

two years ago, but there is a proposal to reinstate it now that the neuropathy problems associated with its use have been reduced. Unfortunately, NHS seems reluctant to approve the proposal and reinstate funding.

More positively, following the ibrutinib success, WMUK trustees have addressed the pressing need to continue expanding the services offered to patients and continue campaigning and lobbying for better treatment. One decision is to employ some paid part time help for administration, freeing time for trustees with Chair Roger Brown to do the more complex lobbying and networking with partner organizations, including pharma. We are recruiting more trustees, particularly those with special skills, such as IT website development and social media. Finally, we have approved in principle the development of a UK Waldenström's hub, where a small number of leading specialist doctors can tackle the fundamental problems of poor survival rates in UK compared with Europe. It is likely that this group will also further develop a trials hub and look at potential new treatments, hopefully with the help of some pharma funding.

Finally, the date of Sunday, July 1 has been put aside for the WMUK Doctor/Patient Summit at the Royal Society of Medicine, 1 Wimpole Street, London W1G 0AE. There will be a dinner on Saturday evening, June 30. All are welcome. Details and booking at [www.wmuk.org.uk](http://www.wmuk.org.uk).

**Roger Brown, WMUK reporting from Pole Hill, Exactly 0°West, Epping Forest (once home of Lawrence of Arabia).**

## AUSTRALIA

**IWMF strong support for WhiMSICAL at the Annual Meeting of the American Society of Hematology (ASH)**

Following the abstract and poster presentation at ASH, IWMF organized briefing meetings with important blood cancer organizations. These included Leukemia & Lymphoma Society, Lymphoma Coalition, and international hematologists and members of the IWMF Scientific Advisory Committee. Broad subjects discussed included:

- Validation of data involving patient input compared to entry by clinical staff; extension of patient-reported outcomes within the WhiMSICAL database;
- Initiatives from major blood cancer groups to spread WhiMSICAL through social media; recruitment initiatives backed by clinician endorsement from major treatment centres;
- Targets to triple participation in WhiMSICAL database to achieve "big data" goal of 1,000.

*International Scene, cont. on page 21*





Carl Harrington (IWMF President), Dr. Ibrahim Tohidi-Esfahani, and Associate Professor Judith Trotman (at ASH 2017 Poster Session)

To participate in WhiMSICAL, go to:  
[www.wmozzies.com.au/index.php/whimsical/](http://www.wmozzies.com.au/index.php/whimsical/)

IWMF President Carl Harrington, in one important meeting, joined WhiMSICAL database principal investigators Associate Professor Judith Trotman and Dr. Ibrahim Tohidi-Esfahani with Dr. Gwen Nichols, chief medical officer of the Leukemia & Lymphoma Society. Joint initiatives for WhiMSICAL were approved.

The key message at all meetings was “WhiMSICAL is a tool for every WM patient to consider their living document, to increase their health literacy and engage them in their healthcare.” Other current WhiMSICAL plans cover a WhiMSICAL presentation during a breakout session at the May IWMF Educational Forum, submission of an abstract for IWWM10 (the worldwide WM researchers meeting to be held in New York in October) and publication of the next WhiMSICAL newsletter.

### Improvements in WMOzzies talk-list and website

David Young, resident in Byron Bay, a beachside town located in the far northeastern corner of New South Wales, has enabled the talk-list to include photos and graphics with articles posted.

WMOzzies members' postings on the talk-list have had increasing focus on participation in clinical trials. There has been particular interest in the incidence of adverse events associated with specific treatments.

Chris Doe, a WMOzzie who resides in Adelaide – one of the few Australian cities to not have convict history – has provided his web expertise to remove a glitch in joining new members. Chris has provided his invaluable expertise for the operation of the WMOzzies website for three years.

**Andrew Warden, WMOzzies, reporting.**

## BETWEEN DECEMBER 1, 2017 AND FEBRUARY 28, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

**Charles T. Ackerman Jr.**  
Christine and Vartkes Apkarian  
**Jeff Atlin**  
Shelly Sinukoff  
**Dr. John H. Austin**  
Paula Austin  
**Janet Bashford**  
Tony Peterson  
**John Bernloehr**  
Ann and Jim Lipkowitz  
**David Bingham**  
Gail and Shawn Hanna  
**Gene Bogdan**  
Daniel Janusek  
**Allan Bosswick**  
Marcia Bosswick  
**Frank J. Bowden**  
Marsha G. Collins  
**Charles S. Bryan**  
Trudy and Stanton Fadden  
Robert and Ruth Fowler  
Nils and Edna Stout  
**Len Clancy**  
Edward Goldberg  
**Galen Weare Clough**  
Mary Beth Braitman  
Kathryn Braun  
The Fred Braun Family  
Craig and Diane Cruz Burke

**Galen Weare Clough (cont.)**  
Michael and Patricia Cracraft  
Eric Dawes  
Michele French  
Stacy and Jama Hostetler  
IceMiller Legal Counsel  
Ann O'Hara  
Kathy Peed  
Hugh G. and Diane C. Sweeney  
**Leo Cohen**  
Shirley Cohen  
**Edward Cohen**  
Nancy Finken  
**Ransom Coleman**  
Anonymous  
**Karl Coyner**  
Katherine Coyner  
**Ann M. Cross**  
Nicolas DiCiaccio  
**Leda Danzig**  
Ronald Danzig, MD  
**Theresa Dugan**  
James Brolly  
Fran Steel  
**Nicole Dunn**  
Joseph and Lynn Dunn  
**John Eldridge**  
Anonymous

**Kenneth Ewen**  
Penelope Ewen  
**Frances Fagan**  
Anonymous  
Sandra Martin  
Mrs. Debra Wayne  
**John R. Faulkner**  
Laureen Faulkner  
**Carolyn Ferrigni**  
Alice F. Rooke  
**Norma Fienberg**  
Anonymous  
**Wayne Fitz**  
Janice Fitz  
**John Flanzer**  
Samantha Flanzer  
**Jerry Fleming**  
Phil Cacioppo  
Vince and Susan Santa Maria  
**Dr. Michael Fry**  
Elaine Moen  
**Richard Fusco**  
Janet Fusco  
**Mafalda Giustiniani**  
Simona and Michelle Cimato  
**Brig Savinder Nath Gulati**  
Sneh Gulati

**Vic Hachenburg**  
Ken and Ann Rothrock, Bill, Cathleen, Riley and Haddie  
**Deanna Harrison**  
Anonymous  
Nana Yaa Ansa  
Hiva Bradshaw  
Caitlin Broome  
Emily Caven  
Ashley Clough  
Amanda Croft  
Bob and Rebecca Davis  
Kelly Doroshenk  
Ted and Sue Doroshenk  
Linda Gross  
Holly Haney  
Rita and Colin Harding  
Kathy Armstrong Hobbs  
Jeff Hubert  
Caityn Kitts  
Greg and Maria Markovich  
Bob and Terry McCabe  
Kimberly McCabe  
Renea Soula  
Sherwyn Tenia  
Jeremy Turner  
Maria Voegel  
Andrew Zabala  
**John Huysman**  
Kent and Jane Wold

**BETWEEN DECEMBER 1, 2017 AND FEBRUARY 28, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

**K. Edward Jacobi**  
Katharine McCleary

**William S. Johnson**  
Denise Cypher

**Robert Kallish**  
Merrill S. Puopolo

**Dudley Killam**  
Joe and Pam Amejka  
Anonymous  
Susan Egitto Asher  
Margot Curtis Simpson  
John Farnworth  
James and Jill Feig  
Deborah Halpern  
Joyce Ishimoto  
Carol Jones  
Jennifer, Dan and Emily Killam  
Stephen Maschue  
Larry Maver  
Jim Zapp and Beth McGlynn  
Matt Volla  
William and Barbara Weber  
Terri Wells  
Wesley and Kay Lynn West  
Peter Young, Col., USAF (Ret.)

**Bill Kowaleski**  
Carol Kowaleski

**Dr. Lisa Jane Krenzel**  
Anonymous  
Elizabeth and Richard Devereaux  
Robert Finkel  
Lisa M. Goldberg  
Nancy Handelman  
Haroules Badini Family  
Lloyd and Sheila Hoffman  
Erin and Joshua Kane  
Warren and Claire Kozak  
Martin and Sylvia Kreithen  
Emily Sharp and Jack Martin  
Paul Millman  
Rebecca Neary  
David Ray, M.D.  
Lesley Rosenthal  
Mary Anne Rothberg and  
Andrew S. Rowen

**Dr. Lisa Jane Krenzel (cont.)**  
Ernest Rubenstein  
Elizabeth Szancer and Tom Zoufaly  
David and Sheri Tabacoff  
Frances Thorndike  
Neil Josephson and Chia Wang

**Dorothy Kuveke**  
Paul Kuveke, Jr.

**Michael Carl Lesmister**  
Gay Lesmister

**Patricia E. Lore**  
Joseph Lore

**Charles Lyons**  
Paula Spiegel

**Mary Clare Mahoney**  
Francis and Carolyn Maginnis

**Daryl Martin**  
Carol E. Martin

**George Coe & Laurence Massaron**  
Susan Coe

**William S. McIlrath**  
Harry and Eleanor Poehlmann

**Millie Miller**  
Edward Goldberg

**Kenneth Miller**  
Keith Miller

**Carolyn K. Morris**  
Maynard Morris

**John S. Myers**  
Tanya, Greg and Jonathan Isley  
SDC Group, Inc.

**Boyd Nelson**  
Anita Nelson

**Judy Nolting**  
Earl Nolting

**Donna Olson**  
Suzette Sanchez and Family

**Karen A. O'Reilly**  
Brian O'Reilly, Jr.

**Roy C. Parker**  
Bill Bass

**Jo Ann Parrish**  
Michael & Stacie McEniry

**Karen Pindzola**  
J. Ander and Kathy Pindzola  
Sharon Resnik

**Dr. Richard Podgorski**  
Mary Podgorski

**Lillian Coslow Pollak**  
Linda Nelson

**Sharon Potesman**  
Susan and Ira Bernstein

**Neil Rehner**  
Susan Rehner

**Rodney Reindl**  
Sharon Reindl

**Bob Resnik**  
Sharon Resnik

**Steve Robbins**  
Kathleen Battle

**Domenico and Marie Rocchio**  
Anthony Rocchio

**Susan Rubenstein**  
Susan and Ira Bernstein

**John G. Sanderson**  
Sharon and Allie Sanderson

**William M. Schieber**  
Susan Schieber

**Kim Schmucki's Beloved Mother**  
Lisa Wise

**Donald I. Smith**  
Jack and Kathy Patrona

**Arnold Smokler**  
Fred and Lynn Bickle  
Donald and Kathryn Wolgemuth

**Burton Strnad**  
Susan and Steve Schnoll

**Robert Trischler**  
Mary Ellen Trischler

**Charles Vassallo**  
Lucrezia Vassallo

**Jon Warren**  
Neal Kendall  
Steven and Christine Talbott

**Jerry Weinstein**  
Deb Weinstein

**Jack Whelan**  
Cindy Furst  
Jennifer Killam  
Bill and Connie Paul  
Lauren Wendel

**Marcia Wierda**  
Evelyn Hamberg  
Judy Motman and Family  
Betty Lou Terhaar  
Andy and Tracie Wierda  
Ken Wierda

**Aren Jennifer Wish**  
Joel Wish

**Erich Wolters**  
Edward Goldberg

**Chown Wucherpfennig**  
Phyllis Stanchfield

**Ron Yee**  
Angelique Draftz  
Tom and Karen Myers  
Sharon Resnik  
Vince and Susan Santa Maria

**Jan Zimmerman**  
Brad Zimmerman

**Albert Zucker**  
Jeff and Julie Kuhn

**BETWEEN DECEMBER 1, 2017 AND FEBRUARY 28, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:**

**Rafat Abonour, MD**  
Barbara and Tom Hennig, MD

**Linda Adamany**  
Anonymous

**Dr. Ranjana Advani**  
Bonnie MacMaster Andersen

**John Albert**  
Suzanne M. and  
Douglas M. Smith

**All those who create and produce communication for IWMF**  
David Skolnick and Marilee Morris

**All with Waldenstrom's**  
Thomas Armstrong

**Dr. Stephen Ansell**  
Phil Cacioppo

**Gail Arcari**  
Carol DeBerry  
Harold and Phoebe Lorenson

**Doris Nannok Axelson**  
Andrea Baker  
Nancy Bergdorf  
Katherine Cartier  
Ronette DeGrey  
Deene DeGrey  
Rene Hauser  
Barbra Hyman  
Kathi Johnson  
Tania Jones  
Caityn Kitts  
Carol Noble - Potts  
Caryn Thomas Poliquin  
Meghan Rangel  
Mark Stokes  
Wanda Torres  
Regina Tyyska

**Thomas Baker**  
Ted and Almie Baker

**Greg Bien**  
Julie Bien

**Sherry Boguchwal**  
Jonathan Boguchwal

**Peg Bohanon**  
Kathleen Bohanon  
Michael and Lise Bohanon  
Diana Williams

**Kathy Boldrey**  
Kathleen Boldrey

**Don and Mary Brown**  
Katharine H. Charney  
Ormel and Lois Prust

**Kyle and Deborah Brunelle**  
Thad and Sylvia Raushi

**Dr. Jorge Castillo**  
Joseph and Carol Wielgus

**Sherman Choy**  
Greg Choy

**Roy J. Clites**  
Susan Clites

**Maria Colosi**  
Vivienne Fontaine

**Dennis and Amy Daraghy**  
Daniel and Terry Odell

**Mark Davey**  
Jim and Pat Davey

**Julie Davidson**  
Julie and Wade Davidson

**Dr. Robert Dean**  
Michael Jackson

**Pete DeNardis**  
Edward Goldberg

**Caroline and Steve Dew**  
Marty Zumbrunnen

**Glen Durmas**  
Charlotte P. Doss

**Jon Dwinell**  
Mr. and Mrs. Daniel Dahl

**Marty Edelman**  
Marty and Carol Edelman  
Paul and Vivian Grossman  
Bud Kahn  
Carol Levine

**BETWEEN DECEMBER 1, 2017 AND FEBRUARY 28, 2018, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:**

**Einstein Healthcare Network  
Montgomery, Department  
of Hematology & Medical  
Oncology**  
Doug Achuff

**Dr. Christos Emmanouilides**  
Fred and Lynn Bickle

**Manuel Fernandez**  
Tami Klerr

**Dr. Mathew Frank**  
Meryl and Robert Selig

**Thomas Jessen Frantz**  
Drs. Timothy and Kimberli Frantz

**Linda Gallivan**  
Mary Hatfield

**Dr. Morie Gertz**  
Phil Cacioppo  
Bill and Gretchen Hannaford  
Miriam and Akiva Ron

**Deanna Gilman**  
Ellen and Arthur Pincus

**Dr. Sandra J. Ginsberg, MD**  
Florence and Bob Brodkey

**Edward Goldberg**  
Anonymous  
Sue August  
B.E. Bassler  
Cynthia Bell and Robert Buckles  
Steven Chess  
Steven and Jill Dorfman  
Geoffery Engel, MD  
Flo Feiner  
Raymond and Sylvia Gilbert  
Barbara Harris  
The Hummers and Strummers  
Richard Lee  
Althea Murphy  
Timothy Plummer  
Janet M Poppe  
Karen and Jonathan Rodgers  
Dianne and Eugene Rogal  
Sandra Paul Saken  
Stephen and Julie Schneider  
Burt C. Skolnik  
Stanley and Betty Weinberger

**Dr. Daren Grosman**  
Linda Pollack

**Susan Hamblin**  
Susan and Gary Hamblin

**Dennis Harleman**  
Ryan and Audra Harter

**Carl Harrington**  
Charles and Marjorie Bosk  
Lesley Weissman-Cook and  
James Cook

Sue Herms  
Barbara Schwartz

**Sue Herms**  
Shirene and John Herms

**Dr. Tom Hoffmann**  
Edward Goldberg

**Bill and Kris Howanski**  
Elizabeth Howanski

**Susan Mack and  
Tom Howenstine**  
Renee Markovich

**Wanda Huskins**  
Sage and Andrew Baron  
Ken Huskins and Ruth Lane

**IWMF Board Members, past  
and present**  
Gerri and Michael McDonald

**The Wonderful Contributors  
to IWMF Connect**  
Pat Getz

**Gail Jaye**  
Matthew and Joy Minner

**Thomas K. Jewell**  
Jim and Holly Jewell

**Kurt D. Johnson**  
Mary T. Johnson

**Ellis R. Kennedy Sr.**  
Betty Jane Ball

**Stephanie Kirejevas**  
Visiting Angels

**Dr. Andreas Klein**  
John Paasch

**Marcia Klepac**  
Anonymous

**Elaine Kozlowski**  
Anonymous

**Dr. Steven Krause**  
Jerry and Karen Eisman

**Doug Kresse**  
Anonymous

**Dr. Robert Kyle**  
Anonymous  
Phil Cacioppo

**Mrs. Charlene Kyle**  
Lisa Wise

**Terry LaBarge**  
Patty LaBarge

**Donald LaTorre**  
Donald and Joan LaTorre

**Janet Livingston**  
Bob and Marysue Livingston

**The Recovery of Steve  
Marblestone**  
Lorraine and Sheldon Alkon

**The Marriage of Aaron Levie  
and Joelle Emerson**  
Maurice and Ruth Levie

**Carol Martin**  
Robert Martin

**Reinhold Mattes**  
Barbara Mattes

**Judith May**  
Gary Hill

**Judith McCoy**  
Richard and Carrie Hill

**Sara McKinnie**  
Phil Cacioppo

**Jean Michiels**  
Edward Michiels

**W. Thomas Myers**  
The Franklin Family  
Betsy Spiker Holcomb  
Jean Myers

**Michael Smith and Gina Odell**  
Daniel and Terry Odell

**Peter and Ann Odell**  
Daniel and Terry Odell

**John Ostrowski**  
John and Deborah Ostrowski

**John Paasch**  
Edward Goldberg

**Lia Palomba, MD**  
Erna and Nancy Brout

**James Paxton**  
The Nielsen Family

**Kelly Primozich**  
Angie Harbaugh  
Keli Kovach Lock  
Deb Richards  
Chris Stetson

**Rita Raimondi**  
Megan Rancier and John  
Schutze

**Stephanie Rakofsky**  
Edward Goldberg

**Thad and Sylvia Raushi**  
Kyle and Deborah Brunelle

**David and Diana Raushi**  
Thad and Sylvia Raushi

**Dan Marder and  
Beth Rheinhardt**  
Dennis and Felice Killian-Benigno  
Daniel Marder and  
Beth Rheinhardt

**Alice Riginos**  
Sandra Ashurst  
Corinna Riginos  
Cynthia Riginos  
Vasilis Riginos

**Judy and Mel Roseman**  
Robert Thompson

**Tom Rousher**  
The Todd Rousher Family

**Dan Rudnitsky**  
Matthew Boroson  
Elaine Bronner  
Rita Catlin  
Jason Catlin  
Carin Chapman  
Michael Gensch  
Jennifer Gilligan  
Megann Hanzel  
Jairo Hidalgo  
Chrissy King

Amy Kirsty  
Mark Leggatt  
Matt Libien  
Cory McCune  
Joe Parrino  
Frank Parrino  
Marie Pesce  
Matt Plessing  
Jennifer Porter  
Dan Rudnitsky  
Lisa Scott  
Tracy Stephenson  
David Wayne  
Samantha Willis  
Michelle Wooten  
Claudine Zamor

**Karen Schange**  
Stephen J. Schange

**Ryan Scofield**  
Diane McKim  
Richard and Karen Scofield  
Tummydrops

**Julius Sherman**  
Valerie Sherman

**Dr. Guy Sherwood**  
Andrew and Sharon Seager

**Jay Singer**  
Anonymous

**Dana Smith**  
Susan Ichikawawa

**Bradstreet Walter Smith**  
Matthew Smith

**Dana Smith**  
Todd Smith  
Tonya Smith Haslop  
John Tenbusch  
Joanne Thomson

**Jill Smith**  
Juli and Dave Zerwer

**Cinda Spavins**  
Terry Holme  
Jeanne and Terry Iannucci  
Shau-Wen Sokol

**Carl and Susan Stoel**  
Stu and Margo Duncan  
Jason Sims and Diana Santiago

**Karen Susio**  
Chris Susio

**Lee Talisman**  
Alisa and Jon Talisman  
Rebecca Talisman

**Paul Thomas**  
Christopher Otley

**Shrilekha Tolat**  
Vikram Tolat

**Dr. Steven Treon**  
Kathleen Battle  
Qui Duong and Ann Lee  
Derek M. Lichter, DDS  
Paul & Patti Patterson  
Harriett and David Pawliger  
The San Diego Area IWMF  
Support Group  
Sylvia Sedman & Mick  
Noordewier

**Nancy Tucker**  
Anonymous

**Anne Marie Vale**  
Marilynne Hameetman

**Ray Valentine**  
Cindy Anders

**Elaine Van Bloom**  
Fred and Dolores Pernerstorfer

**Waldenstrom's  
Macroglobulinemia  
Researchers**  
Daniel Bryska

**Darryll Wartluft**  
Todd Wartluft

**Jacob M. Weintraub**  
Eli Effinger-Weintraub

**Lisa Weldy**  
Mort and Judy Weldy

**Tom White**  
Glenn J. Robak

**Richard Williams**  
Richard and Karen Williams

**Lisa Wise**  
Emilie S. Passow

**James Wohltmann**  
Jocelyn Guerra

**Ken Woltering**  
Kim Agrellas

**Bob Zehner**  
Tom McElwee

**Dr. Lee Zehngebot**  
Bruce and Francine Fox

**Rudy Zunich**  
Rudolf Zunich





International Waldenstrom's  
Macroglobulinemia Foundation

**6144 Clark Center Avenue  
Sarasota, FL 34238**

Telephone 941-927-4963 • Fax 941-927-4467

E-mail: [info@iwmf.com](mailto:info@iwmf.com) • [www.iwmf.com](http://www.iwmf.com)

IWMF is a 501(c)(3) tax exempt non-profit organization

Fed ID #54-1784426

Non Profit Org  
US Postage  
**PAID**  
Manasota, FL  
Permit No. 133

### **Don't Miss the Free IWMF-CancerCare Online/Phone Workshop on WM**

On June 27 Dr. Jorge Castillo of the Dana-Farber Cancer Institute and Dr. Morie Gertz of Mayo Clinic will present on "Progress in the Treatment of WM." You can participate by phone within the United States or stream the program online from anywhere in the world. This program is free, but pre-registration is required. Register online at <http://www.cancercare.org/connect> or by calling the CancerCare HopeLine at 1-800-813-4673. After you have registered, you will receive additional information with connection instructions and other details. If you have a scheduling conflict and cannot participate in the teleconference, you will be able to access a recording of the program on the CancerCare website.



*Funding for this issue of the IWMF Torch provided by a grant from Takeda Pharmaceuticals International Co.*