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## REPORT FROM THE NINTH INTERNATIONAL WORKSHOP ON WALDENSTRÖM'S MACROGLOBULINEMIA

BY GUY SHERWOOD, MD, VICE-PRESIDENT FOR RESEARCH



*Dr. Guy Sherwood, IWMF Vice President for Research*

The Ninth International Workshop on Waldenström's Macroglobulinemia (IWWM9) was held in beautiful, historic Amsterdam on October 5-8, 2016, at the Koepelkerk Conference Hall. As has become customary, following the Workshop an International Doctor-Patient Forum was held October 9, with select speakers from the IWWM9 addressing a large crowd of patient attendees from all over the world.

The chairpersons of IWWM9 were Dr. M.J. Kersten, Dr. Monique Minnema, and Dr. Steven Pals from the Netherlands and Dr. Steven Treon from the Dana-Farber Cancer Institute in Boston. The Workshop Secretariat Christopher Patterson at Dana-Farber once again admirably executed the complex logistics of organizing a Workshop.

Over 250 of the world's leading researchers and clinicians in WM attended. The IWMF was represented by President Carl Harrington; Elena Malunis, Vice President for Member Services; and Guy Sherwood, Vice President for Research. IWMF Trustee Dr. Robert Kyle was also present, as was IWMF Trustee and Scientific Advisory Committee Chair Dr. Stephen Ansell.

Before I start my hopefully brief and lucid summary of the scientific presentations, I would like to highlight a few special events. At the beautiful opening ceremonies held at the Westerkerk Church (Google it!) on the evening of Thursday, October 6, the prestigious Robert A. Kyle Award was presented to a most deserving individual, Dr. Zachary Hunter of the Dana-Farber Cancer Institute in Boston. Many of you may remember Zach as the young, soft-spoken but brilliant researcher from Dr. Treon's lab at Dana-Farber who played a key role in the discovery of the MYD88 mutation in WM. I have followed Zach's "career in WM" closely and was very touched by this marvelous and well-deserved achievement. Also on Thursday evening Lia van Ginneken led a beautiful (and tearful) ceremony where attendees lit a candle on a golden tree in remembrance of family and friends lost to WM. Sadly, I could have lit many candles that evening.

At the closing ceremonies held on the evening of Saturday, October 8, at the Scheepvaartmuseum



*At the opening ceremonies of IWWM9, the Robert A. Kyle Award was presented to Dr. Zachary Hunter of the Dana-Farber Cancer Institute. From left to right, Dr. Steven Treon, Dr. Kenneth Anderson, Dr. Robert Kyle, and Dr. Hunter. At the closing ceremonies, Dr. Kenneth Anderson, also of the Dana-Farber Cancer Institute, received the Jan Gosta Waldenström Award.*

*Report from the Ninth, cont. on page 2*

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*Report from the Ninth, cont. from page 1*

(the National Maritime Museum of the Netherlands – a spectacular museum and a thrill for me personally as I love to sail) the Jan Gosta Waldenström Award was presented to two very deserving individuals: Dr. Kenneth Anderson of the Dana-Farber Cancer Institute in Boston and Dr. Roger Owen of Leeds Teaching Hospital, Leeds, UK (Dr. Owen is currently a member of the IWMF Scientific Advisory Committee).

I have attended a number of these Workshops dating back to IWMF4 in Kos, Greece, in 2007, and this year I marveled at the large number of attendees, particularly the new faces, in Amsterdam. The Workshop followed its customary format: 12 sessions of 4-5 short 15-minute lectures, a poster and oral presentation session, and two “Great Debates” sessions.

As listed below, the scientific program was divided into sessions highlighting particular topics. The diagnostic workup of WM has been altered significantly with the discovery of the roles of the MYD88 and CXCR4 mutations in WM. In fact, the presence of these mutations has overshadowed the previous standards in the diagnosis of WM. Clearly, in the near future the diagnosis of WM will include genetic evaluation with respect to these two mutations, and genetic evaluation will become the norm. Nonetheless, WM patients will be heartened to know that bone marrow biopsies are still very much indicated, as microscopic analysis and flow cytometry offer important information and direct, to some extent, the potential treatment strategies.

Session topics were: **Session 1:** Diagnostic Workup of WM; **Session 2:** Predisposition in WM; **Session 3:** Malignant Transformation in WM; **Session 4:** Genomic Landscape in WM; **Session 5:** Plenary Talks in WM; **Session 6:** Myddosome Signaling: What have we learned? **Session 7:** CXCR4 WHIM Mutations and WM Pathogenesis; **Session 8:** Non-MYD88 and CXCR4 Signaling in WM; **Session 9:** BTK Directed Therapy in WM; **Session 10:** Poster Viewing Reception and Short Oral Presentations of Selected Abstracts; **Session 11:** Novel Therapeutic Approaches for WM; **Session 12:** Great Debates in WM; **Sessions 13 and 14:** Management of Specific Disease Morbidities in WM; **Session 15:** Discussion: When should autologous transplant be offered to WM patients?

The amount of information was, to say the least, overwhelming, and rather than go into great detail about each presentation, I was tasked with giving a general overview of the conference, focusing particularly on the two Great Debates: “What should be the frontline standard for treatment of WM?” and “What should be the goal of therapy in 2017 for WM patients?”

Dr. Kyle (Session 1) reminded the attendees that only symptomatic WM should be treated. This may change in the future, but for the time being this mantra still stands.

*Report from the Ninth, cont. on page 3*



The IWMF Torch is a publication of:

International Waldenström's Macroglobulinemia Foundation  
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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.

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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.

With the advent of new techniques in genetic testing, we will see increased knowledge regarding predisposition to the development of WM in families where WM has been diagnosed in a family member. We may also be able to predict the development of WM in individuals with immune system dysfunction, particularly defects in T-cell immunity.

Dr. Linda Pilarski from Alberta, Canada, (Session 3) has long been a proponent of the idea of multiple clones and clonal evolution in WM. We are well aware that IgM-MGUS is a precursor to WM in all cases. Simply put, WM is a relatively active disease in terms of genetic transformation, and we now know that, in part thanks to Dr. Pilarski's hard work and dogged determination, multiple clones of WM usually exist in patients.

Session 4 highlighted the discovery of the MYD88 and CXCR4 mutations in WM that have revolutionized the study of WM. Research is ongoing to determine what other mutations exist in WM and how these new and yet-to-be-discovered mutations may lead to its development. The first day ended with a plenary session (Session 5) that discussed, among other topics, the mechanism of resistance to newer treatments in WM such as ibrutinib/Imbruvica, clinical data supporting the impact of the CXCR4 mutation on more advanced and aggressive disease, and WM-specific serial flow cytometry assays to evaluate treatment response.

The second day of the conference started with a few sessions (Sessions 6 and 7) in molecular biology that focused on the MYD88 complex and signaling as well as an in-depth look at the implications on a molecular level of the CXCR4 mutation(s). All are complicated topics that required a few trips to the coffee urns for refills. The afternoon continued with Session 8 in molecular biology, this time reviewing non-MYD88 and CXCR4 signaling in WM, in particular the B-cell receptor (BCR), BCL2 expression (BCL2 is a regulatory protein implicated in cell death), and, finally, Dr. Ansell's discussion of his research in the regulation of IgM secretion in WM.

The day's sessions ended with a series of lectures focused almost exclusively on ibrutinib/Imbruvica therapy in WM. Dr. Constantine Tam from Australia presented an exciting lecture on a newer BTK inhibitor BGB-3111 (somewhat akin to ibrutinib) that has demonstrated some very good preliminary results thus far in its trial of previously treated WM patients.

The conference then adjourned to a new locale for Session 10 where a number of posters were exhibited and short oral presentations were also held. A highlight was the presentation of the Young Investigator Awards (YIAs), 11 in total, with 9 sponsored by the IWWMF and one each sponsored by the European Waldenström Network and WM-Italy. One needs to remember that at the previous IWWM8 (in London, 2014) only 5 YIAs in total were presented. Shall we try for 15 or 20 at IWWM10 in 2018? The names of these deserving individuals, as well as short summaries of their work, are

posted on the IWWMF website at [iwwmf.com/research/research-strategy](http://iwwmf.com/research/research-strategy)

The final day (Saturday, October 11) of the IWWM9 conference addressed clinical management of WM. In Session 11, newer and emerging therapies for WM were discussed: BCL2 inhibitors, checkpoint inhibitors (a novel class of immunotherapy agents that inhibit the suppression of the normal antitumor immune response by the tumor itself), newer monoclonal antibodies that target the plasma cell component of the WM tumor. The session concluded with a tremendously exciting (for me at any rate) presentation by Dr. David Maloney from the Fred Hutchinson Cancer Research Center on the emerging adoptive immune therapy field using bio-engineered CAR T-cells (that is, using the body's own immune system, with a few modifications) to kill the WM cells.

As is customary at these events, two Great Debates were held (Session 12) where difficult questions were argued by leading WM clinicians and researchers. These debates hold great interest for the WM patient community because they often significantly influence the therapeutic strategies used by clinicians in the treatment of WM.

The topic of the first debate: "What should be the frontline standard for treatment of WM?" Five expert clinicians presented their cases. Dr. Christian Buske from Germany (who is, incidentally, a 2015 IWWMF-LLS Strategic Research Roadmap grantee) prefaced the discussion with a rather sobering state of the union address with respect to the difficulties encountered by WM clinicians and health care policy directors when discussing which treatments are, and should be, available to WM patients.

Clearly, each separate country dictates availability of treatments based on economic realities or economic priorities. The UK, for example, has a poor record of making new treatments available (as has Canada, sadly). Health economists often refer to dogma when justifying their decisions to restrict treatment choices. In WM these include: few randomized Phase III trials, no well-established treatment standards, and variable adherence by individual countries to follow existing recommended guidelines (such as the National Comprehensive Cancer Network [NCCN] guidelines). Obviously, the rarity of WM compared to other, more common cancers has a tremendous impact on these decisions as well. We simply have to eliminate WM (i.e. cure it) to resolve that issue or find some way to influence and educate the health care policy "deciders."

In any event, the following topics were debated: the demonstrated efficacy of bendamustine and combination therapies with bendamustine and perhaps the need for fewer cycles – four as opposed to the standard six (Dr. Mathias Rummel, Germany); the cheap and effective CDR therapy – Cytoxan, dexamethasone, and rituximab (Dr. Evangelos Terpos, Greece); the tried-and-true use of nucleoside analog combinations that have proven effective in WM and, in



particular, their use in the treatment of Bing-Neel syndrome despite the risk of transformation (Dr. Véronique Leblond, France); the fading popularity of bortezomib in spite of newer oral agents of the same class that have less neurotoxicity (Jorge Castillo, USA); the rise of ibrutinib to become the new standard for frontline treatment of WM (Meletios Dimopoulos, Greece). No clear winner was declared, and once again the availability of some of these relatively newer agents, given economic realities, was invoked.

The second debate was perhaps a little more contentious, certainly from the perspective of WM patients who were in attendance. The question “What should be the goal of therapy in 2017 for WM patients?” was discussed. Moderator Dr. Eva Kimby (Sweden) opened the debate by asking why complete responses are so uncommon in WM. Dr. Alessandra Tedeschi (Italy) took the aggressive position that, with recent research supporting new modes of attack, complete response is a goal that can be achieved. In response, Dr. Efsthais Kastiris (Greece) argued that, with the development of new types of treatment in recent years, disease control should continue in 2017 to be the goal of therapy for WM. Clearly we want a cure, but in reality we may have to settle with disease control for now. This did not sit well with the patients, as we are all anxious to rid ourselves of WM for good. Truthfully, however, the treatments currently available at this time unfortunately do not offer frequent complete responses, and WM patients may have to patiently await results from continued research and clinical trials.

The scientific conference continued with two sessions related to the management of specific disease complications in WM. Session 13 addressed peripheral neuropathy (Dr. Shirley D’Sa, UK); Bing-Neel syndrome or brain involvement in WM (Dr. Monique Minnema, the Netherlands); kidney failure, which is rare but present in some cases (Dr. Josephine Vos, the Netherlands). Session 14 covered amyloidosis in WM (Dr. Ashutosh Wechalekar, UK, and Dr. Giampaolo Merlini, Italy); hyperviscosity, and cryoglobulinemia (Dr. Marvin Stone, USA). Rapid and effective control (and possible eradication) of the disease appear to underlie the current treatment strategies.

The conference ended with Session 15 on the role of autologous transplants in the treatment of WM. Presenters seemed to be polar opposites on this issue: Dr. Charalampia Kyriakou from the UK, a leading expert in autologous transplants in WM, argued that transplants are effective and grossly underutilized in the treatment of relapsed WM patients, whereas Dr. Jean-Paul Fermand from France was quite opposed to the use of autologous transplants in WM, given newer options for patients.

My overall perspective of this spectacular and informative scientific Workshop (each successive one is better and better and more encouraging for this WM patient) is that controversy still exists with respect to what is the best treatment strategy for WM. This is not surprising, given the fact that there exists so much heterogeneity among individual WM patients and that

the best treatment for one may not be applicable to another. Nonetheless, it is clear that we are making increasingly important discoveries in the pathogenesis of this disease, and this progress impacts positively on future treatments available for WM and greatly increases the likelihood of increased survivability and less toxic treatments.

As I reflect on this Ninth International Workshop on WM (IWWM9), my impression can be summed up in three observations: we are seeing increasing interest in WM from researchers and clinicians who were not previously involved with WM (WM now seems to be a “sexy beast” in the minds of the hematology research community); we are now entering the era of individual genetic testing to better determine individual targeted therapy (we are all similar yet different); and the advent of immunotherapy, such as CAR T-cell therapy and directed specific immune checkpoint inhibitors, promises that we are nearer than ever to a cure or, at the very least, long-lasting remissions.

There is more work to do, more research needs to be funded, more patients need to participate in clinical trials, and we as WM patients can feel encouraged by all the efforts of researchers and clinicians around the world. Many thanks again to the conference chairs and specifically to the Workshop Secretariat Christopher Patterson and his team from Dana-Farber.

The end is near (not the zombie apocalypse), and we will see exciting new positive developments in our journey with WM. Researchers need our focused encouragement in terms of research funding, and we as WM patients and our loved ones need to continue to support each other as we have in the past. In the interim we must also “live, laugh, and love often.”

Donate and Participate!

The next International Workshop on Waldenström’s Macroglobulinemia will be held in New York City in October 2018.

*Complete information on IWWM9, including the Abstracts of all sessions, can be found at: [wmworkshop.org](http://wmworkshop.org)*

\* \* \*

*You may detect a “theme” throughout this Torch issue, which takes its cue from the article “Three Cheers for Volunteers!” by Michael Sesnowitz on page 7. One particular volunteer I am honored to write about is Dr. Guy Sherwood, whose report on IWWM9 is the lead article for this issue. If you are a frequent reader of the Torch, you are by now familiar with Guy’s inimitable writing style and his way of “translating” difficult medical subjects so that they are easier and more interesting to read. He is also a regular speaker at IWMF Ed Forums, where his engaging personality and sense of humor show through in his presentations. Guy has volunteered for the IWMF in many other capacities through the years, notably serving for several terms on the Board of Trustees and writing publications for patients. Now he also serves as Vice*

*Report from the Ninth, cont. on page 5*



*President for Research. I remember back to my early days on IWMF-Talk, when I was reading about Guy, a physician diagnosed at a young age and with a young family, and the story of his travails before, during, and after his autologous stem cell transplant. At that time, I didn't imagine that I would have the opportunity to get to know Guy well, but I have been fortunate. I can attest to the fact that he is just as*

*engaging and funny in person, as well as compassionate and caring. He works for the IWMF while he maintains a busy in-hospital practice and teaches medicine to aspiring physicians in Winnipeg, Canada. So, three cheers for a "Guy" who is a volunteer extraordinaire!*

Sue Herms, IWMF Trustee, Research Committee Member, Torch Associate Editor

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## IWMF MEMBERS SPONSOR NINE YOUNG INVESTIGATOR AWARDS

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As part of its commitment to furthering the advance of research specific to WM, the IWMF has been instrumental in the support of the biennial global conferences known as the International Workshops on Waldenström's Macroglobulinemia (IWWM), which provide WM researchers and clinicians an opportunity to share their research findings and collaborate on methodologies.

To promote innovative research, the International Workshops sponsor an award program for young medical specialists, researchers, and postdoctoral fellows specializing in the area of WM. The Young Investigator Awards (YIAs) are intended to develop knowledge and skills in WM, thereby stimulating research applicable to the development of medical innovations that save and sustain patients' lives.

The IWMF and several of its international affiliates have since 2014 contributed to the program by funding up-and-coming research investigators to attend the International Workshops on Waldenström's Macroglobulinemia.

The IWMF is grateful to the following named US donors, whose generosity helped us sponsor Young Investigator Awards for each of the talented researchers listed below.

Researcher: Constance Baer, MLL Munich Leukemia Laboratory, Munich, Germany.

Sponsors: Lenny Martin and Carrie Wells.

Researcher: George Chen, Bing Center for Waldenström's Macroglobulinemia, Dana-Farber Cancer Institute, Boston, MA, USA.

Sponsors: Joseph and Yvonne LoRe, in memory of Frank J. LoRe.

Researcher: Eric Durot, Department of Hematology, Centre Hospitalier Universitaire de Reims, France.

Sponsors: Mr. and Mrs. Ronald Branscome, Mr. Don Handal.

Researcher: Simone Ferrero, Department of Molecular Biotechnologies and Health Sciences, Division of Hematology, University of Torino, Torino, Italy.

Sponsor: Anonymous.



*Young Investigator Awardees at IWWM9 proudly display their plaques commemorating the honor conferred on them in Amsterdam. The IWMF funded the awards for nine of these promising young researchers. At the far right: IWMF President Carl Harrington, Dr. Steven Treon, and Dr. Enrica Morra.*

Researcher: Josh Gustine, Bing Center for Waldenström's Macroglobulinemia, Dana-Farber Cancer Institute, Boston, MA, USA.

Sponsor: Anonymous.

Researcher: Shahrzad Jalali, Mayo Clinic, Rochester, MN, USA.

Sponsor: Roy Langhans.

Researcher: Aneel Paulus, Mayo Clinic, Jacksonville, FL, USA.

Sponsor: Ken Wierda.

Researcher: Nickolas Tsakmaklis, Bing Center for Waldenström's Macroglobulinemia, Dana-Farber Cancer Institute, Boston, MA, USA.

Sponsors: Mr. Gordon VanderBrug and Mrs. Catherine VanderBrug.

Researcher: Josephine M. Vos, MD, St. Antonius Hospital, NL.

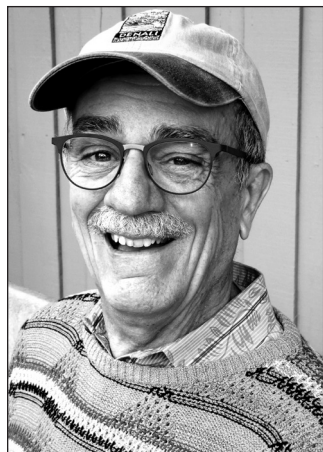
Sponsors: Catherine Brotzman, Michael and Carol Sesnowitz.

Congratulations to the awardees and many thanks to these generous donors for helping support and inspire the next generation of WM researchers!

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## PRESIDENT'S CORNER

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Welcome to 2017!

When I was in Amsterdam in October to attend IWWM9 (the International Workshop on WM), someone said “When I was still employed, I was a project manager: figuring out the timing, the resources and the best way to get things done. Now that I have WM, I’m a project manager again, but I’m focused on managing my WM.” As someone

whose whole marketing career involved managing multiple products, those words rang true to me. So, how do **you** plan to manage your WM this year?

Let’s take a look back at 2016 and see what the IWMF did to provide you with resources to manage your WM, and then let’s look at what 2017 might bring. Of course, everything the IWMF does reflects our simple but compelling vision: “To support everyone affected by WM while we advance the search for a cure.” Remember, with the IWMF you are never alone!

Key highlights of 2016:

1. We made great progress on the IWMF-LLS Strategic Research Roadmap:
  - a. In February, we received 18 high quality research proposals from around the world.
  - b. In May, we held the second Strategic Research Roadmap Summit, in New York City, and reaffirmed the four key areas of research focus: Bone Marrow/Tumor Microenvironment; Immunotherapy; Cell Signaling and Genomics/Epigenetics.
  - c. In August, we provided \$1.7M funding for three key Roadmap projects and a fourth project outside the Roadmap, bringing our total research spending since 1999 to over \$10M.
  - d. In November, we issued a new RFP (Request for Proposals) to about 250 prominent researchers, asking for new proposals that we would consider for funding in 2017. The number we are able to fund will depend upon donations.
  - e. In December, we issued a new RFP for a specific project related to WM and amyloidosis. While not strictly part of the Research Roadmap, this project was made possible by a targeted *iwmf.com* donation from a generous WMer.
2. We helped fund the Ninth International WM Workshop (IWWM9); over 250 physicians and

researchers met, for 3 days, to share and collaborate about future needs and plans. As part of this work, and through the generosity of nine donors, we funded nine recipients of the Young Investigators Awards (YIAs) to attend IWWM9. These are the young researchers that we hope, over time, will provide continuing leadership in our efforts to find a cure for WM.

3. We enhanced member support by:
  - a. Naming eight new Support Group Leaders in the US and establishing a new IWMF affiliate (WM-Scandinavia) to provide support to patients in Denmark, Sweden and Norway. The new leaders are providing personal support when and where needed.
  - b. Expanding LIFELINE capability via more contacts and more topics. If you are too far from a support group or the next meeting is not soon enough, just pick up the phone and you can speak to someone who’s been in your situation.
  - c. Holding or supporting very successful educational forums around the globe. Overall, more than 800 WMers personally attended education forums in the US, Canada, France, the UK, Belgium, Germany, Italy, and the Netherlands.
  - d. Adding two new partners: Lab Tests Online and Triage Cancer. See what they offer at *iwmf.com*
  - e. Creating five new, downloadable pamphlets about treatment options that, via a grant from one of our pharmaceutical partners, have been translated into French, Spanish, Italian, traditional Chinese, simplified Chinese and, for the first time, German. These pamphlets will guide you, and your oncologist, in choosing the best treatment for you. Go to *iwmf.com/media-library/download-iwmf-publications* to review these new publications.
4. Breaking our 2015 donations record with an incredible 2016 total.

What can you expect, in 2017, from the IWMF Board of Trustees and the IWMF Office that can help you manage your WM?

1. The 2017 IWMF Educational Forum will be in Phoenix, AZ, May 19-21. The theme will be *Imagine a Cure: Mapping Our Future*. See page 19 for more details and registration information. There’s no better way to build your knowledge about WM while making life-long friends.

*President's Corner, cont. on page 7*

2. Our US support groups and affiliates will continue a steady stream of meetings and educational events. Look for these on our events calendar at [iwmf.com](http://iwmf.com)
3. We will announce a new round of Roadmap research projects in August 2017. The number of projects we support will depend upon the donations you make and the quality of the proposals we receive.
4. The third Strategic Research Roadmap Summit will be in October, in New York City. This Summit will ensure we remain on the best track to finding a cure.
5. We will be updating IWMF-Talk, making it easier to use. From early in 2017 it will be called IWMF-Connect. Use it to tap into the collective wisdom and experience of WMers worldwide.

6. We will update our free publications *Medical Tests* and *Living with WM*. These updates ensure you have the latest tools to help you manage your WM.

I wish you the best as you manage your WM in 2017. Rest assured that we are hard at work providing you with the tools we think will help you. And remember, with the IWMF you are **never** alone. Call upon us and your fellow WMers for the support you need.

Stay well!

Carl

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## THREE CHEERS FOR VOLUNTEERS! REFLECTIONS ON THE STATE OF THE FOUNDATION

BY MICHAEL SESNOWITZ, VICE PRESIDENT FOR FUNDRAISING

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A few months ago participants on IWMF-Talk discussed the best charities to support financially. The focus of the discussion was on CEO and other executive salaries and the portion of dollars donated that actually go to program support. There are many ways that charities can be evaluated. One way is to see if the charity is meeting its mission. Another is to see if the charity is operating efficiently, using the lion's share of its budget to fund its programs. The IWMF believes that these two metrics should both be used. That is, it's not sufficient to be efficient if you're not meeting your mission, and it's not sufficient to meet your mission if you're not doing so efficiently.

The mission of the IWMF is:

- To offer mutual support and encouragement to the Waldenstrom's macroglobulinemia community and others with an interest in the disease.
- To provide information and educational programs that address patients' concerns.
- To promote and support research leading to better treatments and, ultimately, a cure.

We meet the first two parts of our mission by providing an online forum (IWMF-Talk) through which we can support each other in real time; by providing the LIFELINE as a means for patients to learn and receive support from other patients who have experienced treatments being contemplated; by providing contact information for WM medical specialists throughout the world who have agreed to provide consultations to patients and their physicians; by providing Support Groups throughout the United States as well as in other countries; by creating and maintaining an informative website; by

publishing the *Torch* which summarizes recent research and treatment options and connects readers with the organization and with each other; by publishing booklets and fact sheets that help explain the mysteries of WM and the treatments available; by providing highly informative Info Packs to the newly diagnosed; and by holding the Educational Forum each year in the United States where attendees can learn from the world's leading WM experts about the most recent research and most effective treatments and can network with one another. We provide these services at no charge and rely on donations to cover our costs. The sole exception is the Ed Forum for which we charge a modest fee that helps defray the cost of meals.

We meet the third part of our mission by providing funding for the most promising research projects in the world that address WM. We accomplish this with the help of our Scientific Advisory Committee (SAC) made up of the world's leading researchers. Last year we awarded an additional \$1.2M of grants to researchers who responded to the Strategic Research Roadmap's "Request for Proposals" with the most innovative and promising proposals. We also committed another \$500,000 to the continuation of very promising work by Dr. Treon's team at the Dana-Farber Cancer Institute. Since 1999, the more than \$10,000,000 in research we have sponsored has led to publications in some of the most prestigious medical journals in the world, including the *New England Journal of Medicine*. This research has resulted in a better understanding of our disease and has led to better treatments. It has brought us closer to a cure.

*Three Cheers for Volunteers, cont. on page 8*

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We believe our members support us because they believe that we are accomplishing our mission. But are we doing it efficiently? We believe we are.

Last year the Sarasota Community Foundation conducted a compensation-and-benefit survey of non-profit organizations in the greater Sarasota area. The results were reported by organization size. With an annual budget of \$1.7M, we fall in the middle of the \$1M-\$2.5M group. Nonprofits in this group reported having a full-time staff of 15 and a part-time staff of 9. Assuming that part-time workers work half time, a full-time staff of 15 and a part-time staff of 9 are equivalent to a full-time staff of 19.5. By contrast, the IWMMF has a full-time staff of 2 and a part-time staff of 4, so our full-time equivalent staff is 4, only one-fifth the size of the average nonprofit organization in our category.

How do we manage to meet our mission with such a small staff? Volunteers! We are able to do all we do with a very small staff because we rely heavily on volunteers.

Who are these volunteers and just what do they do? Let's start with our President, Carl Harrington. Leading the IWMMF is a full-time job, and Carl works long hours on our behalf with no pay. It would take too much space to enumerate everything he does. Suffice it to say that he oversees all operations of the IWMMF, establishes and maintains relationships with pharmaceutical companies and other nonprofit organizations like LLS and LRF, and provides the leadership that enables us to continue to meet our mission.

Unlike most non-profit boards, the IWMMF Board of Trustees is not just a group that sets policy, it's a group that implements the policies it sets. And this hardworking volunteer board is supplemented by a large number of other volunteers who do everything from creating and publishing the *Torch* to soliciting and reviewing research proposals.

Every article in the *Torch* is written by a volunteer, including the popular Doctor on Call column. The *Torch* is edited by Alice Riginos, who spends countless hours lending her considerable editorial skills to the IWMMF. The booklets and other IWMMF publications are all written by highly skilled volunteers. All those who staff the LIFELINE are volunteers. All Support Group Leaders are volunteers. All those who plan and implement the annual Ed Forum are volunteers, as are all the speakers who enlighten us. The website was created, and is maintained, by volunteers. IWMMF-Talk is maintained by Peter DeNardis, volunteer and Board member.

Dr. Stephen Ansell of the Mayo Clinic chairs the Scientific Advisory Committee composed of 18 of the world's most

prominent WM specialists. They are all volunteers who help us set research policy and review the proposals and reports we receive. Every member of the IWMMF Research Committee is also a volunteer.

Our small staff in Sarasota supports all these volunteers. We could not function without our wonderful staff, but it is the volunteers that enable us to keep their size so small.

Last year Carl Harrington surveyed our volunteers and estimated that they spent roughly 23,000 hours working for the IWMMF. Assuming that 2,000 hours represents a full work year (40 hours per week, 50 weeks per year), those volunteer hours translate into 11.5 full-time equivalent employees. It is these volunteers that allow us to operate effectively with just 4 full-time equivalent employees and allow us to use the vast portion of donations programmatically.

In almost everything we do, we aim for class A. Class A researchers to conduct WM research, a class A website and publications to educate our members, a class A Ed Forum, and so on. But there is one area in which we shun class A: real estate. Class A in commercial real estate refers to buildings that have high quality finishes, state of the art systems, exceptional accessibility, and a market presence. The IWMMF maintains its headquarters in Sarasota, FL, where class A commercial properties rent for as much as \$60 per square foot annually. If you visit the IWMMF offices, you won't find any mahogany, but you will find modestly appointed offices that rent for \$7.40 per square foot annually and house a small staff of dedicated professionals who strive daily to help us accomplish our mission.

If you believe, as we do, that the IWMMF is a good steward of your money, accomplishing its mission efficiently, we hope you will choose to support us as generously as you can.

As always, every dollar donated to the Research Fund will be used to support an approved research project.

*Michael Sesnowitz joined the IWMMF Board of Trustees in 2012 as Chair of the Fundraising Committee. An economist by training, Michael's credentials in both academia and government attest to an active and impressive career. Equally noteworthy is the number of positions he has held in a volunteer capacity. The IWMMF is indeed fortunate to have this career-long volunteer "on Board." The Torch conveys to Michael its best wishes upon his recent retirement from the Virginia Commonwealth University.*

## Have Your Say

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

# MAJOR GIFTS TO THE IWMF

**RESEARCH PARTNERS** – For a commitment of \$50,000 per year over 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.

## Research Partners

David & Janet Bingham Research Partners Fund of the IWMF

Robert Douglas Hawkins Research Partners Fund of the IWMF

Michael & Rosalie Larsen Research Partners Fund of the IWMF

Carolyn K. Morris Research Partners Fund of the IWMF

W. Thomas Myers Research Partners Fund of the IWMF

K. Edward Jacobi 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.

## Named Gift Funds

Baker Family Research Fund of the IWMF

Dr. Morie A. Gertz Research Fund of the IWMF

Gary Green Research Fund of the IWMF

Caroline & Harry McPherson Research Fund of the IWMF

Lynn Martin & Carrie Wells Research Fund of the IWMF

Gail Murdough Member Services/Research Fund of the IWMF

Sesnowitz Family Research Fund of the IWMF

If you have discretionary giving power and would like to help move our Research and Member Services programs 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 possible 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)

## Imagine A Cure Campaign Progress Report

As of November 1, 2016

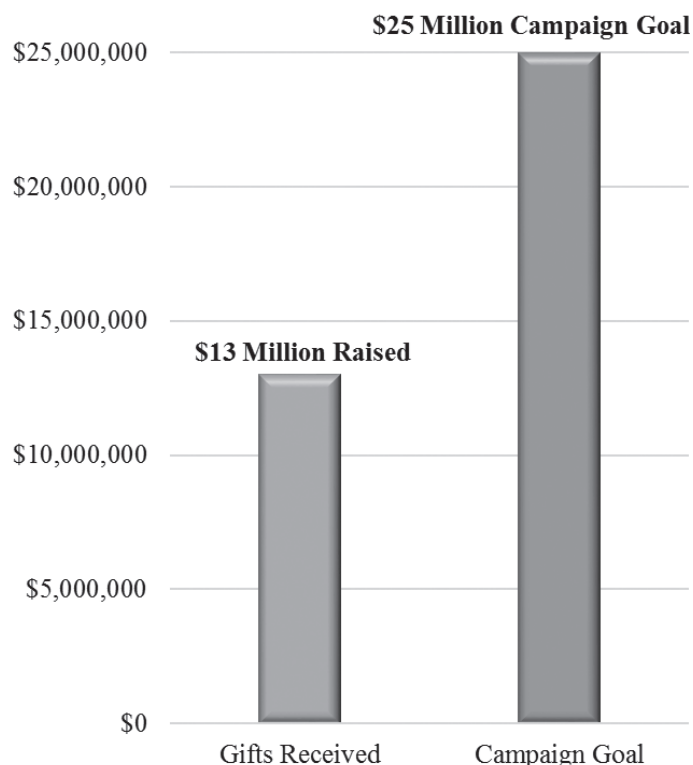
### Reach Out to Others for Support

The IWMF Support Groups are the perfect place to talk with and share experiences with other people affected by WM, including patients, family members, and caregivers. The groups provide mutual support and education and offer the opportunity to discuss concerns with others who share similar experiences. Counting our International Affiliates, the IWMF now has 56 support groups as follows:

- US – 34 Support Groups
- International – 22 Support Groups across 14 affiliates (Australia, Argentina, Belgium, Canada, Finland, France, Germany, Ireland, Italy, the Netherlands, Spain, Denmark/Norway/Sweden, Taiwan, UK)

You can find the locations of all IWMF-affiliated Support Groups at:

[iwmf.com/get-support/us-and-international-support-groups](http://iwmf.com/get-support/us-and-international-support-groups)



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# IN MEMORIAM: KAREN FOSSE PINDZOLA

## 1944 - 2016

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When word comes that we have lost a member of our Foundation, all share a sense of sorrow and loss, and this was especially true when the word came that Karen Pindzola had died peacefully at home on the morning of July 13. Many members of the IWMF remember Karen for her volunteer service, as well as her warm and welcoming manner.



*Support Group Leader Karen Pindzola speaking to the Philadelphia Support Group.*

An active member of the Board of Trustees from 2004 to 2008, Karen compiled the first version of the IWMF Support Group Leaders' handbook, which has proved to be invaluable to the many leaders over the past decade. In her role of Support Group Leader of the Philadelphia Support Group, a post she shared with her husband, Dan Pindzola, for fourteen years, Karen touched many lives through her tireless dedication, her invaluable support, her strength and patience. Many remembrances of Karen's kindness and generosity circulated on IWMF-Talk as the report of her death became known, and many remembered her as an active participant offering sage advice based on her years of experience.

It was important to Karen that her WM community know and understand that she did not pass away from Waldenstrom's, but from sarcoma resulting from radiation used successfully 50 years ago to treat Karen for Hodgkin's disease, another form of lymphoma.

The words of President Carl Harrington, who was a Philadelphia Support Group member during Karen's time as leader, sum up sentiments expressed by many: "Karen holds a special place in my heart as she is the one who helped me when I was first diagnosed, welcomed me to the Philadelphia Support Group, and 'took care of me' at my first Ed Forum in Atlanta in 2007. She will be greatly missed. I am glad to have had a chance to see her and her husband, Dan, at the May 15, 2016, Philadelphia Support Group meeting."

Her survivors include her husband of fifty-two years, Daniel M. Pindzola, of York, PA; her son, J. Ander Pindzola and his



*On display at the memorial service for Karen, a photo of Karen and Dan Pindzola with their children and grandchildren.*

wife, Kathy, also of York; her daughter, Lauren P. Courtney and her husband, Andrew, of Falls Church, VA; as well as her sister, Lynn Demos, of Greenbelt, MD; and her five beloved grandchildren, Grace, Olivia, and Jude Pindzola, and Sasha and Hanna Courtney.

A Memorial Service celebrating Karen's life was held on Saturday, September 17, at the Unitarian Universalist Congregation of York. Members of the Philadelphia Support Group were welcomed by Karen's family and friends. At the reception that followed, important aspects of Karen's life were recalled in a unique and personal way. The display of her Girl Scout sash, decorated with an array of honor badges, and other Scout memorabilia showed that the value of service to others was rooted in her early years. Most impressive, however, was the exhibit of Karen's watercolor paintings. Her family members recalled her pleasure while painting at Plein Air festivals along the Eastern Shore. Those who had known



*Snowscape by Karen.*

*In Memoriam, cont. on page 11*





*Paintings by Karen were on display as well. Members of her Support Group who had known her for years were surprised to learn that Karen was an accomplished artist.*



*At the reception following the memorial service, items on display, including her Girl Scout awards, evoked the youthful Karen Fosse Pindzola.*

Karen as their Support Group Leader were surprised by the revelation that she was also an artist of considerable talent.

Long-time readers of the *Torch* will recall that, writing for the column Support Group News, Karen would often note the attendance of the Philadelphia Support Group's mascot, "the little white dog Heidi" who was always said to have enjoyed

the refreshments. Heidi certainly would have been pleased with the "French Crackers," an old-fashioned type of butter cookie baked by Karen's sister, Lynn, from an old family recipe to serve at the reception. This was another personal touch that made Karen's service and reception so very special for all who knew and loved her.

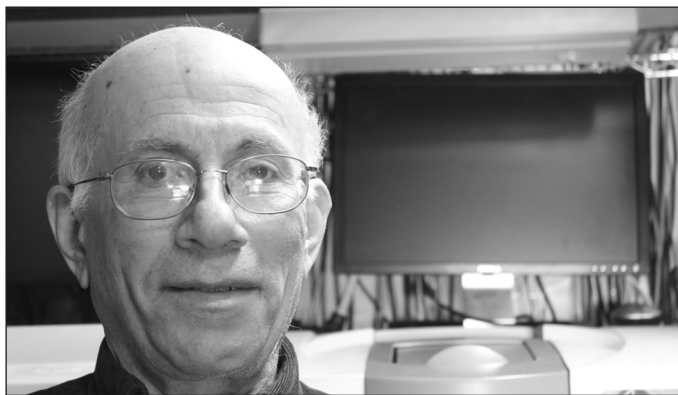
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## IN THE TORCHLIGHT

BY MICHAEL RAY JACOBSON

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Michael Ray Jacobson was born in Pittsburgh, PA, in 1950. After graduating as one of four valedictorians of Allderdice High School, he attended Harvard College and Cornell University for his undergraduate physics and doctoral astronomy degrees, in 1971 and 1977, respectively. In 1973, he married Dr. Simone Ellen Jacobs, a chemist. They moved to Tucson, AZ, in 1975 and had three children there. Mike was on the staff of the College of Optical Sciences from 1977 through 1991, when he and Simone founded a spectrophotometry test laboratory, Optical Data Associates. Tragically, Simone died in 1998, at 52, from chemotherapy. He married Shoshana, a psychotherapist, in 2000, and added two grown stepdaughters to his family. Mike continues to run the company on his own, and has no plans to retire. He is active in his synagogue, sings in the choir, goes regularly to the gym, solves difficult crossword puzzles, and loves working with his hands. Over the years, he has written scores of parodies and poems, best



*Dr. Michael Ray Jacobson in his spectrophotometry test laboratory.*

described as enlightened doggerel. He is honored to have the poem that follows, written for his 45th college reunion book, published in the *Torch*.

*In the Torchlight, cont. on page 12*

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## *On My 45th College Reunion*

As I complete solar loop forty-five  
Since graduation, I here will contrive  
A doggerel ditty on staying alive  
As my life's seventh decade I hope to survive.

I live in Tucson, where the sky is not drab  
That's where I run my spectroscopy lab  
My clients send samples from field or fab  
I send them results and put fees on their tab.

The kids are in cities that all end in "o"  
Tivon, wife, and son call their home Tokyo,  
Shira inhabits the shore in Chicago,  
Natan's residing in north San Diego.

My first wife, a chemist and math whiz, Simone,  
In ninety-eight died, an event I bemoan  
The chemo that killed her was accident prone  
This left me and our children so strangely alone.

After three months of mourning, I no longer tarried  
To mobilize Michael and get me remarried  
The women I met then were many and varied  
I soon found my Shoshi, the motion was carried!

We've been together now, seventeen years  
She's supported my strengths and supplanted my fears  
Her own psychotherapy business career,  
Has earned her respect from her clients and peers.

For my sixtieth birthday, I wrote a short ode  
And set it to music, and at my abode  
I sang at my party of how I plateaued  
And the subtle decline that the future forebode.

When I turned sixty-one, my chronic anemia  
The family doctor found rather unseemly, a  
Specialist recognized from academia  
Waldenstrom's macroglobulinemia!

This type of lymphoma strikes not in one's prime  
And often is indolent, failing to climb  
But this may indeed be the very first time  
That this B-cell explosion has been set to rhyme!

I go to the gym, but the small strains and sprains  
Are harder to heal, and hold on to my gains  
As muscle tone weakens and memory wanes.  
Apnea, tinnitus – the nuisances reign!  
Then last June came viral encephalitis,  
Along with its cousin, acute meningitis  
Two weeks in the hospital, felt like detritus  
My first as an inpatient since tonsillitis.

Then I got out and I went back to work.  
Those days I was down almost drove me berserk,  
Getting back to my business ejected the murk!  
My purpose and passion were powerful perks.

So I still have the energy, lambently glowing  
Despite all the evidence that I am slowing  
The lab and my family both keep me going,  
Such blessings betoken a more subtle growing!

*– Michael Ray Jacobson*



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# MEDICAL NEWS ROUNDUP

BY SUE HERMS, IWMF TRUSTEE AND RESEARCH COMMITTEE MEMBER

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## **NICE Reverses Decision and Agrees to Recommend Ibrutinib Treatment for CLL in the United Kingdom**

– There is hope that a recent development in the United Kingdom may bode well for the future of ibrutinib treatment of WM patients there. At press time, the United Kingdom's National Institute for Health and Care Excellence (NICE) said that it could now recommend ibrutinib (Imbruvica) treatment for relapsed chronic lymphocytic leukemia (CLL). Previously, a NICE appraisal committee had recommended against ibrutinib treatment in CLL because of its cost, but the decision has been reversed following Johnson & Johnson's agreement to cut the drug's price. A NICE appraisal committee had also provisionally refused to approve ibrutinib for the treatment of relapsed WM, but a final recommendation is anticipated shortly.

## **Canadian Oncology Drug Review Committee Recommends Against Reimbursing Ibrutinib for WM**

– The Expert Review Committee of the pan-Canadian Oncology Drug Review (pCODR) issued its final recommendation to not reimburse ibrutinib (Imbruvica) for the treatment of WM patients who have received at least one prior therapy. The Committee made this recommendation because it was unable to conclude, based on the available evidence, that there is a net clinical benefit of ibrutinib compared with other appropriate treatment options, and that there is considerable uncertainty with regard to outcomes such as overall survival, progression-free survival, and quality of life. The Committee acknowledged the drug's ability to control disease symptoms, its ease of administration, and its improvements to quality of life. The Committee concluded that, at the submitted price, ibrutinib is not cost-effective in WM patients who have had at least one prior therapy and that there is potential for a substantial budget impact with ibrutinib. The submitted price of ibrutinib was \$90.65 per 140 mg capsule; at the recommended dose of 420 mg/daily, ibrutinib would cost \$7,614.60 per 28-day therapy course vs. an approximate weighted average of \$2,493.15 for the mix of standard therapies. The pCODR was established in Canada by the provincial and territorial ministries of health (with the exception of Quebec) to assess cancer drugs and make recommendations to the provinces and territories to help guide their drug reimbursement decisions.

**Report Discusses Transformation in WM Patients** – A report appearing in the *American Journal of Hematology* from the Bing Center at Dana-Farber Cancer Institute discussed transformation to diffuse large B-cell lymphoma (DLBCL) in patients with WM. Transformation means a switch from a slow-growing indolent cancer with an indolent clinical history to a more aggressive appearance under the microscope and a more aggressive clinical course. The report points out that transformation rarely occurs in WM – in this

study, 20 patients out of 1,466 experienced transformation. The incidence of transformation is approximately 2% at 10 years and can occur in treatment-naïve as well as heavily treated patients. Most patients presented with extranodal (outside the lymph nodes) involvement, and the DLBCL cells expressed BCL6 and BCL2 but not CD10. All patients were treated with chemoimmunotherapy (a combination of chemotherapy and immunotherapy drugs). The median survival from transformation was 2.7 years, and the median overall survival was shorter for transformed patients vs. those who did not transform (estimated 9 vs. 16 years).

## **Bing Center Releases More Data on Atrial Fibrillation Associated with Ibrutinib Use**

– Atrial fibrillation (AFib) is a known adverse event among patients with B-cell malignancies, including WM, treated with ibrutinib. A letter to the editor of the *American Journal of Hematology* from the Bing Center at Dana-Farber Cancer Institute identified 12 of 112 WM/LPL patients (10.7%) treated at its institution with ibrutinib who were subsequently diagnosed with AFib; 50% of these patients had a prior history of the condition. The cumulative incidence of AFib at 1, 2, and 3 years was 5.4%, 7.1%, and 8.9%, respectively; the median time to the first AFib event on ibrutinib for all 12 patients was 14.2 months, and patients with a prior history had a shorter time to AFib. Cardiologic intervention following the event included initiation of anti-coagulation therapy with warfarin or rivaroxaban (Xarelto), anti-arrhythmics, beta-blockers, cardioversion, calcium channel blockers, and ablation with dual-chamber pacemaker placement. Eleven of the 12 patients (92%) with an AFib event continued on ibrutinib following intervention, although 5 (42%) patients had their ibrutinib dose reduced to 280 mg/day following the event. The reason for ibrutinib-related AFib remains under investigation, although inhibition of cardiac PI3K-Akt signaling has been suggested.

## **Algorithm Proposed for Managing Ibrutinib-Related Atrial Fibrillation**

– An article published by Cancer Network in its online journal *Oncology* discussed a proposed algorithm for physicians to use to assess the appropriate treatment for patients who develop ibrutinib-related atrial fibrillation. The authors, from Huntsman Cancer Institute in Utah, also recommend routine consultation with a cardiology specialist to determine the most appropriate intervention to manage stroke risk. The proposed algorithm can be used to guide drug choices, minimize the potential for drug-drug interactions, and involve and educate the patient in treatment planning. The authors concluded that there must be a compelling reason to initiate anti-coagulation therapy for ibrutinib-related AFib, as to date there have been no reported cases of thrombotic stroke due to this condition; they placed more emphasis on the importance of rate/rhythm control and continuation of ibrutinib

*Medical News Roundup, cont. on page 15*

therapy, and less on the need for anti-coagulation. They also suggested that clinical trial validation using their model is needed. Anyone wishing to obtain a copy of this article for his or her physician may contact this column's author via e-mail at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net) or the IWMF Office.

**Retrospective Study Discusses Association of Kidney Disease with WM** – The incidence and prognostic impact of nephropathy (kidney disease) related to WM has been largely unknown. This retrospective study, published in the *British Journal of Hematology*, assessed WM-related nephropathy in a group of 1,391 WM patients seen at the Bing Center at Dana-Farber Cancer Institute, in whom 44 cases were identified. The cumulative incidence was estimated as 5.1% at 15 years. There was a wide variation in kidney pathology, including amyloidosis, monoclonal IgM deposition disease/cryoglobulinemia, lymphoplasmacytic lymphoma infiltration, light chain deposition disease, and light-chain cast nephropathy, among others. The median overall survival in patients with confirmed WM-related nephropathy was 11.5 years, shorter than survival for those without nephropathy, which was 16 years. Survival was better in patients with stable or improved renal function after treatment. Based on these findings, the report recommended that monitoring for kidney complications should be considered in the surveillance of WM patients.

**Joint Study Looks at Secondary Malignancies in MGUS, Multiple Myeloma, and WM** – A joint study from the Bing Center at Dana-Farber Cancer Institute and the Mayo Clinic in Rochester evaluated the risk of secondary malignancies in patients with MGUS, multiple myeloma (MM), and WM. In recent years, the survival of these patients has improved due to improvements in anti-cancer and supportive therapy; however, the risk of secondary malignancies has increased, thought to be due to a combination of environmental and disease-related factors, as well as treatment. This review, published in *Leukemia & Lymphoma*, concluded that current data support an increased risk of myelodysplastic syndrome/acute myeloid leukemia in patients with these conditions. Although exposure to alkylating agents, nucleoside analogs, immunomodulatory agents, and/or stem cell transplant might increase the risk of secondary myeloid malignancies, there is evidence that MGUS patients, who are typically not exposed to these agents, also have an increased risk of these same malignancies. The present data strongly suggest an inherent increased propensity of developing myeloid malignancies, which is present irrespective of therapy exposure. The risk of other secondary hematologic malignancies or solid tumors is less well established. In WM patients specifically, there seems to be an increased risk for acute myeloid leukemia, diffuse large B-cell lymphoma, thyroid cancer, and melanoma. The biology behind such relationships remains elusive.

**Bing Center Closes Phase II Trial of Idelalisib for WM** – The Bing Center at Dana-Farber Cancer Institute reported its experience in *Leukemia & Lymphoma* on the

use of idelalisib in a Phase II trial of previously treated WM patients. In preclinical studies, the MYD88 L265P mutation also promoted activation of the PI3K pathway in WM cells, and exposure to idelalisib, a PI3K inhibitor, induced robust tumor cell killing. This clinical trial, activated in September 2015, had an original accrual goal of 30 patients; the actual enrollment was 5 patients, who received idelalisib orally at 150 mg/twice daily. Four patients were evaluable for response and exhibited stable disease on idelalisib; however, 4 of the 5 experienced Grade 3-4 (severe) increases in ALT, a liver enzyme, indicating possible liver toxicity. In March 2016, Gilead Sciences stopped 6 trials of idelalisib combination therapies in patients with hematologic malignancies due to an increased mortality rate associated with cytomegalovirus reactivation and *Pneumocystis* pneumonia. Although these infections were not seen in the Bing Center patients, its study was also closed in March. The study authors concluded that further development of idelalisib in WM would have to be considered in the context of clinical trials in which different dosage regimens could be evaluated in order to reduce the possibility of liver toxicity.

**ARGX-110 Development for WM Ended** – Argenx announced that it has ended its collaboration with the Leukemia & Lymphoma Society to develop its lead oncology drug ARGX-110 for the treatment of refractory WM. Under their collaboration agreement signed in 2014, Argenx and LLS had agreed to contribute a combined \$4.5 million toward a Phase II study of ARGX-110 in WM. ARGX-110 is a monoclonal antibody that targets CD70. The company will continue to develop the drug for T-cell leukemia and acute myeloid leukemia.

**Idera Suspends Trial of IMO-8400 for WM** – In other disappointing news, Idera Pharmaceuticals has decided to suspend its Phase I/II trial of IMO-8400 for WM treatment. The decision was made not for safety concerns but because updated results suggested a limited clinical opportunity for IMO-8400 as single agent therapy in WM. IMO-8400 is a novel antagonist of the Toll-like receptors TLR7, 8, and 9.

**Updated Clinical Trial Data Released for BGB-3111 in WM** – BeiGene, Ltd. presented updated clinical data from an ongoing Phase I study of its oral BTK inhibitor BGB-3111 in WM patients at the 9th International Workshop on WM in Amsterdam. The preliminary clinical data demonstrated that BGB-3111 is well-tolerated and highly active in WM, with an overall response rate of 92%, including a major response rate of 83% and a very good partial response rate of 33%, at a median follow-up time of 8 months. This dose escalation trial was conducted in Australia, New Zealand, and the US, with the ongoing study dosage established at 160 mg/twice daily. Adverse effects were generally mild and self-limiting, with the most frequent being upper respiratory infection, diarrhea, petechiae/bruising, and nausea. One patient developed atrial fibrillation. More serious adverse effects included two cases

*Medical News Roundup, cont. on page 16*

of anemia and one case each of renal artery thrombosis, bronchiectasis (permanent enlargement of and damage to bronchial tubes), thrombocytopenia (low platelet count), high blood pressure, cryptococcal meningitis, and neutropenia (low neutrophil count). No serious hemorrhage was reported. Analysis of patient response by genomic characteristics is ongoing.

**Exome Sequencing Reveals Recurrent Germ Line Variants in Patients with Familial WM** – Familial WM cases and the clustering of B-cell proliferative disorders among first-degree relatives of WM patients have been reported. Nevertheless, the possible mechanism of inherited susceptibility to familial WM remains largely unknown. In a study reported by Dana-Farber Cancer Institute, the Spedali Civili di Brescia in Brescia, Italy, and the Harvard School of Public Health, whole exome sequencing was performed on germ line DNA (DNA passed through reproductive cells) that was obtained from 4 members of a single family, 3 of whom had WM. Additionally, 246 independent, unrelated WM cases were screened as well as a control population without WM. Specific germ line DNA variants in the LPTM5 and HCLS1 genes were the most recurring ones, present in all 3 affected members of the index family but not in the unaffected family member, detected in 8% of the unrelated familial cases, present in 0.5% of the nonfamilial cases, and found in less than 0.05% of the control population. This report was published in *Blood*.

**Study Looks at Long-Term Outcomes of Allogeneic Transplantation in Relapsed WM** – A multicenter study published in the journal *Biology of Blood and Marrow Transplantation* looked at long-term outcomes of 144 relapsed WM/LPL patients who received allogeneic stem cell transplantation. The data were obtained from the Center for International Blood and Marrow Transplant Research database from 2001-2013. Of this number, half received myeloablative (high intensity) conditioning, and half received nonmyeloablative (mini-allo or reduced intensity) conditioning. The median age of patients was 53 years, and the median time from diagnosis to transplantation was 41 months. Thirteen percent failed prior autologous stem cell transplantation. In this study, progression free survival, overall survival, rate of relapse, and non-relapse mortality at 5 years were 46%, 52%, 24%, and 30% respectively. Patients with chemo-sensitive disease and better pre-transplant disease status prior to transplantation experienced superior overall survival, and there were no significant differences in progression-free survival based on the conditioning regimen. The most common causes of death were primary disease and graft-vs-host disease (GVHD). While allogeneic transplantation yielded durable survival in select patients, the study authors concluded that strategies to reduce mortality from GVHD and post-transplant relapse are necessary to improve this approach.

**Information Presented on Seasonal Flu Vaccination for CLL Patients on Ibrutinib** – A letter appearing in *JAMA Oncology* from the National Institutes of Health looked at the efficacy of seasonal influenza vaccination in patients with chronic lymphocytic leukemia (CLL) treated with ibrutinib (Imbruvica). Patients with CLL have impaired responses to vaccines because of hypogammaglobulinemia (deficiency of normal antibodies) and chemotherapy. Influenza vaccination was offered to CLL patients enrolled in a Phase II trial of ibrutinib. From October 1 to November 21, 2014, 19 patients received 1 dose of inactivated trivalent vaccine, either Fluzone high-dose or standard dose. Antibody titers were measured before and 3 months after vaccination. Up to 74% of the patients achieved protective titers against one or more of the influenza strains after vaccination, thereby indicating that an antibody response to vaccination is possible in patients receiving single-agent ibrutinib. Consequently, routine immunization against influenza should be considered in accordance with the Centers for Disease Control and Prevention (CDC) recommendations for immunocompromised patients.

**Phase II Trial of CLR 131 in Multiple Myeloma and B-Cell Lymphomas to Open** – Cellectar Biosciences will open a Phase II clinical trial of its investigational compound CLR 131 in relapsed/refractory multiple myeloma and B-cell lymphomas during the first half of 2017. The trial identifier number is NCT02952508. CLR 131 uses a small-molecule lipid (fat) compound that delivers radioisotope iodine-131 directly into tumor cells. Participants with lymphomas will receive a single dose of the drug infused over a period of 30 minutes and will have the option of receiving a second dose 80-160 days after the first dose, depending on their physicians' assessments. The drug is currently being tested in Phase I trials in patients with multiple myeloma, and the US Food and Drug Administration has granted CLR 131 orphan drug status for multiple myeloma.

**Phase III Trial Reports Obinutuzumab and Bendamustine Combination Therapy in NHL** – A multicenter Phase III study looked at obinutuzumab (Gazyva) plus bendamustine vs. bendamustine only in patients with indolent non-Hodgkin's lymphoma who were unable to achieve adequate disease control with rituximab-based treatments. Gazyva is a novel anti-CD20 antibody. This GADOLIN study, reported in *Lancet Oncology*, enrolled 396 patients: 194 received obinutuzumab plus bendamustine and 202 received bendamustine only. Those patients on the combination therapy who did not progress received obinutuzumab maintenance for up to 2 years. The primary endpoint was progression-free survival. After a median follow-up of 21.9 months in the combination arm and 20.3 months in the bendamustine only arm, progression-free survival was significantly longer in the combination arm. Grade 3-5 (moderate to severe) adverse events occurred in 68% of



patients in the combination arm and in 62% of patients in the bendamustine only arm – these included neutropenia (low neutrophil count), thrombocytopenia (low platelet count), anemia, and infusion-related reactions.

**TGR-1202 Being Evaluated in Several Clinical Trials for CLL and Lymphoma** – TG Therapeutics announced that the US Food and Drug Administration granted orphan drug designation for the company's oral, next generation PI3K delta inhibitor, TGR-1202, for the treatment of patients with chronic lymphocytic leukemia (CLL). The drug is currently being evaluated in a Phase III trial for patients with both frontline and previously treated CLL. The company has also begun a Phase I/II trial of TGR-1202 in combination with the proteasome inhibitor carfilzomib (Kypriolix) in patients with relapsed or refractory lymphoma. That trial is enrolling patients at the Center for Lymphoid Malignancies at Columbia Presbyterian Medical Center in New York, and the trial identifier number is NCT02867618.

**Phase I Study Reports Safety of Marizomib in Malignancies including Multiple Myeloma** – A Phase I clinical trial of marizomib (NPI-0052) in patients with advanced malignancies, including multiple myeloma, was published in *Clinical Cancer Research*. Marizomib is a proteasome inhibitor in the same class as bortezomib (Velcade). Marizomib was administered intravenously in 2 dosing schedules to 42 patients. The most common adverse events were fatigue, nausea, diarrhea, and infusion site pain. Marizomib did not appear to cause the severe peripheral neuropathy or hematologic toxicity observed with several other proteasome inhibitors.

*The author gratefully acknowledges the efforts of Peter DeNardis, Wanda Huskins, John Paasch, Colin Perrott, Howard Prestwich, Charles Schafer, Ron Ternoway, and*

*others in disseminating news of interest to the IWmf-Talk community. The author can be contacted at [suenchas@bellsouth.net](mailto:suenchas@bellsouth.net) for questions or additional information.*

\* \* \*

Medical News Roundup enters its second decade of publication with this issue of the *Torch*! The 2006 fall issue of the newsletter introduced Medical Research News, an incisive review of the most recent medical news applicable to blood cancers, especially to WM, edited by Sue Herms.

With a shift of title to the familiar Roundup, this column has run in every issue since then. We all benefit from the hard work Sue does, not only collecting (now with the help of others) scientific news but also presenting in clear and concise format information that has special impact for us, for WMers. And this is but one example of how Sue's volunteerism extends to all of us. Sue is Associate Editor of the *Torch*, and every issue is improved by her collaboration. As Trustee of the IWmf and serving as Chair of the Publications Committee, Sue's volunteer activities expanded to include writing such educational materials as Treatment Options, editing the series of IWmf booklets, and reviewing all correspondence sent out in the name of the Foundation. For the Ed Forum Committee, Sue currently plays a key role in planning the program, in corresponding with the doctors, and in seeing to it that the Forum runs as planned. She is a long-standing member of the Research Committee. As the Roadmap initiative brings increased work for the Committee, Sue is giving considerable time and effort to assure the success of this venture that serves us all. For the IWmf, Suzanne Herms is a volunteer on a super scale! And, owing to her keen sense of humor, it is also a delight to work alongside her.

Alice Riginos, *Torch* Editor

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## FROM A DAUGHTER WHO BECAME CAREGIVER

BY TIARE HOEGERMAN

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*Tiare Hoegerman is the daughter of Jennifer Hoegerman who, when diagnosed with WM, was a "younger WMer" with an active career and young children at home. Jennifer today is a WM survivor of 21 years and still very active. In this open letter to family members (especially the junior members) of WM patients, Tiare combines frank speech with emotion and tenderness in telling how it was, and is, "to be a child of Waldenstrom's."*

To the Parents, the Sons, and the Daughters:

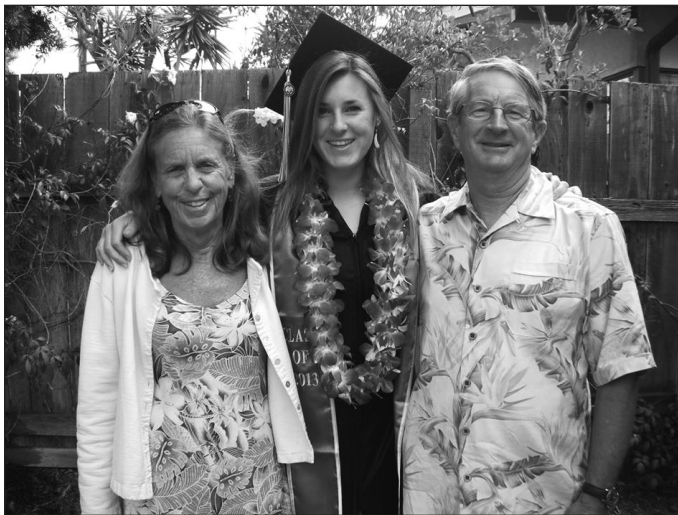
In the 20-odd years since my mom's diagnosis, it feels as if my family has been through every twist, turn, peak, and drop on the rollercoaster ride that is cancer.

I was just 4 years old when my grandpa, a doctor, first discovered something amiss in mom's lab work. The adult conversations about IgM numbers, neuropathy, and life expectancy that ensued went right over my fluffy blonde head, unable to scare me like they surely did my parents and big brother. As I grew older, though, the reality of her diagnosis slowly set in. Now 25, I must admit that I'm still in the process of accepting



*Fulbright Scholar  
Tiare Hoegerman in  
Panama.*

*From a Daughter, cont. on page 18*



*Tiare with her parents, Jennifer and Robin Hoegerman.*

the unpredictable, mysterious beast that is Waldenstrom's. I probably always will be.

Last year, when I agreed to the *Torch's* invitation to share my experience as a daughter **and** caregiver, I had no idea how difficult writing this would be. I'd anticipated blasting out a letter in an hour or so and sending it off to the editors without a second thought.

Not the case.

A page or two of words will never capture what it feels like to grow up watching your mom trudge through cancer. What sentence, no matter how artfully crafted, can fully encompass the sick, sinking feeling in my stomach when her numbers take a downturn and chemo talk comes up again? How can I describe the fear that tightened around my throat each time I saw her in an oncology room bed, never knowing how many more close calls remain for us. Nor can words do justice to the awe I feel in watching her scramble up hiking trails at 64, when years ago the doctors said that her neuropathy should have her wheelchair-bound by now.

I've done many things for Waldenstrom's that I wish I'd never have had to do, at least not by this age. I've cried myself to sleep countless times for it, I've quit jobs and moved home for it, I've learned to be a mother to my own mom for it. Hell, I've even had to assist an enema for it. (Don't ask.)

But as much as it stunted my spirit at times and shaved off my childhood innocence perhaps a little too early, I can't help but give Waldenstrom's its due credit.

There's something about a life-threatening illness, be it your own or that of someone you love, that makes life's little moments more meaningful, life's surface stresses less meaningful. It forces a deeper, more mindful perspective. The words "I love you" carry more weight. Actions as simple as to bring my mom a cup of tea are more purposeful. I don't know how many more opportunities I have to tell her how

much she means to me. I don't know how many more cups of tea I'll get to enjoy with her.

This past December my best friend's dad died of cancer. Nothing in my life has been so heart-crushing, yet deeply beautiful, as standing beside her as she went through the process of hospice, his last weeks, and finally a memorial gathering that none of us could believe was actually happening.

That winter, Kim's life fell completely apart: she had lost her dad – the rock in her family, her friend, her hero.

I watched in awe as Kim, instead of falling apart, took all the love and loss of that difficult season, wrapped the two up together like yin and yang, and slowly began to restore balance in her life. By the spring Kim had transformed into the strongest, wisest, most grounded version of herself that I've seen in the 13 years we've been friends. I am so proud of her. Just thinking of everything that has happened since December fills my heart with pride and my eyes with tears. Kim learned in one big burst the courage and sense of security that I've slowly been learning over the past 20-odd years thanks to my mom's Waldenstrom's.

To the parent worrying about how your diagnosis will affect the kids: I assure you that, although it won't ever be easy, your kids will be fine, just like Kim and just like myself. There's no avoiding the fact that cancer just plain sucks. You can't shield them from that.

Once they get over that part, though, cancer may become the cruelest but most valuable teacher. I know Waldenstrom's has been mine. It wakes me up to life's inconsequential beauties, like the way the blue in my mom's eyes turns more alive and piercing whenever she's by the ocean. Or the way she danced with my brother at his wedding in July, her neuropathic feet kicking up dust and a giant smile on her face, without even a thought of the wheelchair they'd predicted for her years ago. If it were not for her cancer, would I give even half a blink to such things?

To the daughters and sons growing up as caregivers: I hope that, by the time you turn 25, you, too, will have learned more than you ever thought you'd know by that age. I hope your dance with cancer makes you strong and grounded like it has made my friend Kim; I hope it makes you joyful and radiant like it has made my mom. I hope, like me, you can one day find yourself grateful for the hard lessons that cancer has forced on your family, lessons of life, loss, and love. And I hope that you can appreciate every single cup of tea that you get to share with someone.

*After teaching English as a Second Language for 3 years in California, New York, and Costa Rica, Tiare Hoegerman is currently at the Universidad de Panama in the Fulbright English Teaching Assistant Program.*

*Jennifer Hoegerman shared her life with Waldenstrom's in the Torch issue 15.4 (November 2014) pages 15-17.*

**YOU DON'T WANT TO MISS THIS ONE, FOLKS...**

# *22nd Annual* **IWMF Educational Forum**

**May 19-21, 2017  
Phoenix, Arizona**

**Imagine a Cure: Mapping Our Future**



Ever wonder what it would be like to visit Planet WM for one weekend? What if there was a place where everyone spoke the same disease language, learned about symptom management, shared treatment experiences and lab numbers, and knew what it felt like to carry this diagnosis? Look no further than Arizona in 2017! The IWMF Ed Forum is THE place for one-stop shopping for every WM patient and caregiver around the world! Still not convinced you should come? Maybe this will help....

## **TOP TEN REASONS TO BE THERE!**

10. Engage with the world's leading WM experts and superstars.
9. Connect with your old WM friends from across the globe.
8. Meet lots of new WM friends who understand your journey.
7. Attend the exciting Early Bird Session "The ABCs of WM" which is open to ALL, not just newbies.
6. Come see why IWMF President Carl Harrington is right when he states: "You are not alone!"
5. Enjoy the very popular "Ask the Doctor" panel discussion.
4. Mingle at the President's Reception and enjoy the festive Welcome Dinner alongside IWMF Trustees and world-class physicians.
3. Explore a plethora of different and diverse Breakout Sessions addressing multiple issues and hot topics.
2. Are you a Support Group Leader? Be sure to attend the informative half-day workshop on Thursday, May 18, led by Marcia Klepac, IWMF Support Group Coordinator.
1. Do you really need a reason for a springtime escape to relax and recharge in amazing Arizona??? Seriously: Come & Play! Register online at [www.iwmf.com](http://www.iwmf.com) or fill out and mail the registration form enclosed with this *Torch* issue mailing.

Renaissance Phoenix Downtown Hotel  
100 North 1st Street, Phoenix, Arizona 85004  
[www.marriott.com/hotels/travel/phxbd-renaissance-phoenix-downtown-hotel](http://www.marriott.com/hotels/travel/phxbd-renaissance-phoenix-downtown-hotel)  
602-333-0000 • Toll-Free 800-309-8138  
See you in Phoenix!



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# FROM IWMF-TALK

BY JACOB WEINTRAUB, MD

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As we enter the winter season, post holidays, we hope for spring. Looking back, there have been some significant events, including the International Workshop in WM held in Amsterdam. This event always produces important information, especially about new developments, see the report by our Vice President for Research, Dr. Guy Sherwood, on page 1. While discussion of the Amsterdam Workshop did not come up as a topic on this forum, the discussions on IWMF-Talk were extensive and had a wide range of topics. Again, new members joined, and even long standing members raised questions about diagnoses, treatments, and other related topics.

## HUMAN INTEREST/ARTICLES

As always, a multitude of interesting and helpful items were posted regularly, and a full column could be done just using these links. Here are some of the more interesting.

**Wanda H** posted a link to an article titled “Silver Tsunami of Cancer Survivors.” This comes from the NIH-National Cancer Institute and reports a study showing that the aging of the US population will result in a substantial increase in the number of older cancer survivors, particularly age 85 and above. This is expected to place a strain on the ability of the health care system to meet such a growing demand for services.

<http://www.cancer.gov/news-events/cancer-currents-blog/2016/cancer-silver-tsunami>

Wanda also posted a link to an article showing that humor therapy is excellent medicine. Other articles about humor have been posted in the past, but this article has a slightly different perspective, offering some support for medical aspects of humor, including “the science of laughing.”

<http://movies.justchristiannews.com/index.php/2016/09/10/humor-therapy-for-cancer-is-the-best-medicine>

**IWMF-Talk Manager and Trustee Peter DeNardis** posted a link from *Cure* magazine with the title “My Disease Doesn’t Make Me a Hero. I Am a Hero.” This is an inspirational article by a cancer patient who provides a perspective on how to live through those tough moments of dealing with the enormity of our WM disease and its impact on us.

<http://www.curetoday.com/community/samira-rajabi/2016/08/my-disease-doesnt-make-me-a-hero-i-am-a-hero>

Wanda posted the link to an article written by a physician about the influenza vaccine. The article was posted as part of a larger discussion about influenza and other vaccines, a discussion that occurs frequently during flu season. More on vaccines below.

<http://sunriserounds.com/ok-so-i-just-dont-get-it-the-flu-that-is>

Finally, IWMF-Talk editor **Dr. Jacob Weintraub** added the link to an article in *Cure* magazine called “Two Things to Say to Someone with Cancer.” This is a topic relevant to all of us with cancer and provides helpful thoughts about connecting with friends or relatives with cancer.

<http://www.curetoday.com/community/martha-carlson/2016/09/the-only-two-things-you-need-to-say-to-someone-with-cancer?p=2>

## FLU SHOT

Also known as an injection against seasonal influenza, this topic is discussed every year. Although this issue of the *Torch* is published well into winter and the flu season, the discussion is still relevant for the remainder of the season this year and for the next season as well.

*In quoting verbatim the words from the participants in the following lively discussion, Dr. Weintraub is quite correct to quote with accuracy. The words quoted, however, lead to mild confusion when we survey the terminology used in the various posts to designate two different types of injectable flu vaccine. We hear of ‘senior’ (or ‘high dose,’ ‘extra strength,’ ‘strongest one,’ ‘over 65’) versus ‘standard’ (or ‘regular,’ or ‘killed virus’).*

*The website of the Centers for Disease Control and Protection cdc.gov gives us the following terminology: The standard dose flu shot and The high-dose shot (for older people).*

*But there’s more! For the first time, and only recently licensed by the FDA, in the 2016-2017 flu season there is another vaccine against seasonal influenza that is designed to “create a stronger immune response to vaccination.” The stronger response is achieved by the addition of an ingredient called adjuvant. Visit cdc.gov to learn more!*

*Torch Editor*

**Tom C** asked if anyone knows whether WM patients who have completed chemo should get the “senior” (high dose) dose annual flu shot or just the regular one.

**Anita L** reported that her oncologist advised against the “senior dose.”

**Penny J** posted that she has had the “extra strength” flu shot every year since it was offered, with no problem. She noticed that her grandchildren were advised against the “flu mist” nasal immunization. However, this is a live vaccine, and it is not recommended for WM patients, while the standard flu shot is a killed virus.

**Laura E** reported that she received the “senior” flu shot, (strongest one) a few weeks ago while being treated with

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*From IWMF-Talk, cont. on page 21*



Velcade. Laura did not have any problems or reactions. She gets this shot every year.

**Ken L** reported that he, too, takes the “senior flu” shot every year. While Ken says it appears to be fairly effective in preventing serious infections, he also reported that he had the flu at the time of posting and regularly gets flus about twice a year.

IWMF-Talk editor **Jacob Weintraub, MD**, advised Ken that the “flu” shot is specific for 3 or 4 strains of influenza only. The vaccine is fairly good at preventing these very serious infections. He also mentioned that there are many other viruses that can cause “flu like” illnesses. Parainfluenza and adenoviruses are examples of viruses that can cause a flu-like illness with fever and cough. The influenza vaccine would not prevent the flu-like illnesses caused by parainfluenza and adenoviruses.

**Armand T** added that, although he has no empirical proof, he is convinced that the flu shot led to his developing Guillain-Barré syndrome. His oncologist conceded that the likelihood is strong, as Guillain-Barré is, indeed, a rare outcome of the influenza vaccine. So Armand no longer will receive the flu shot.

**Faye L** posted that she received the “over 65 shot,” both this year and last year from the Mayo Clinic. This year is the first time she ever had a reaction – a low grade fever which went away. Faye knows people who also ran a fever after receiving this flu shot but who are not cancer patients.

### IMBRUVICA/IBRUTINIB

When I get ready to write this column for the each new issue of the *Torch*, I say that I will not include discussion of Imbruvica. However, the discussions continue daily online. Some among us are trying to decide if this is the best treatment, others are questioning the side effects that are reported, others are reporting excellent results with minimal adverse effects. Imbruvica’s effect on wound healing was discussed this time around. Atrial fibrillation also was a frequently reported problem.

**Jim D** posted his story of atrial fibrillation (AFib) over the last 30 years, with no treatment at all for this. However, he did have to take an anticoagulant (“blood thinner”) in order to get into the ibrutinib clinical trial. He has had no change in his AFib while taking Imbruvica. After 9 months in the

trial, his IgM has decreased from 7,300 to 3,600, and his bone marrow infiltration is down from 80% to 30%. He reports side effects of hip and back pain bothering him “a lot” and also reports water retention and fatigue. Jim takes a diuretic pill and potassium tablets. He feels fortunate that he never has had palpitations or fainting, nor has he needed cardioversion.

**Sharon T** noted that AFib can cause strokes if not controlled. She is taking such a high dose of antiarrhythmic meds because of Imbruvica that she feels terrible. Her oncologist prefers to have her continue to take the full dose of Imbruvica for now.

There also was some discussion about delayed wound healing. **Pavel I** reported that he stepped onto something sharp two months ago and suffered a small cut on his toe. This wound apparently is not healing; if healing is occurring, it is imperceptibly slow.

**Paul L** suggested that Pavel should give it another month. Paul has been on Imbruvica and had a very similar problem after podiatric surgery on his big toe. The toe finally healed after about ten to eleven weeks. He had to bandage it every day the whole time and had to apply antibiotic ointment to prevent infection.

**Pat G** posted that she is not on Imbruvica but has finished a course of bendamustine, and now is just using IVIg. She has had cuts, scratches, and small burns that take 2 months or longer to heal. Pat wonders if this is a WM issue and not just an Imbruvica issue.

### VELCADE/BORTEZOMIB

While new experiences with Imbruvica continue to be reported, many members are also reporting on treatment with some of the older treatments.

**Carl G** reported that he was to be starting Velcade, with Rituxan to be added at the second cycle. Carl indicated that his hemoglobin is very low and he is experiencing weakness. He had been receiving red cell transfusions. Carl was hoping to keep as active as possible and was asking about results and side effects that others experienced from Velcade.

**Zed F** responded that he was diagnosed with retinal hemorrhages and a very high IgM. He had one plasmapheresis and then started BDR (bortezomib, dexamethasone, Rituxan). He received bortezomib/Velcade subcutaneously. Zed has been tolerating the treatment fairly well, although

*From IWMF-Talk, cont. on page 22*

## HOW TO JOIN IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: [iwmf-talk-subscribe-request@lists.psu.edu](mailto:iwmf-talk-subscribe-request@lists.psu.edu)  
Make sure to enter the word “subscribe” as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a “period” after “edu” or it will reject. Once approved you can post by sending e-mail to [iwmf-talk@lists.psu.edu](mailto:iwmf-talk@lists.psu.edu)
2. Contact Peter DeNardis at [pdenardis@comcast.net](mailto:pdenardis@comcast.net) and provide your full name

he reported mild constipation and some sleeplessness due to the dexamethasone. He has had no peripheral neuropathy (PN), which is often reported by people who have received Velcade. Zed has made a daily practice of walking for about 45 minutes after dinner, even when he is tired following the Velcade infusion. His IgM has decreased from 6000 at the start to below 4000. Zed also takes the antiviral acyclovir to prevent shingles.

**Larry** reported his experience with Velcade. When Larry expressed concern to his oncologist about potential neuropathy, he was offered a reduced schedule for the Velcade. Larry agreed to this, but even with a reduced amount he did develop some minor peripheral neuropathy in his forearms. This lasted for two years and only now is finally dissipating.

**Gerry W** reported receiving 8 cycles of BDR in 2009 with twice-weekly Velcade infusions. Although the treatment was very successful, resulting in complete remission, Gerry ended up with a very uncomfortable case of PN in the lower extremities. The PN did eventually reverse somewhat, but Gerry still has some lingering discomfort. Gerry added that the reported rate of PN is 30% in patients treated with Velcade, so that leaves a majority of 70% who do not experience peripheral neuropathy.

Finally, **Faye L** stated that her treatment with Velcade was the most successful treatment she had received. She began with subcutaneous infusions twice a week, later adding Rituxan and dexamethasone. The major problem she developed was lowered neutrophils. At one point, her neutrophil level dropped into the critical range. She was given Neupogen, which did not help, and then was given Neulasta. The Velcade was stopped after the third or fourth cycle. Her IgM decreased

from over 5000 to 1300, her current level. Faye would not hesitate to take this treatment again if it was offered.

## AGING

Finally, there were a few comments about treatment for the more elderly members of our group.

**Shirley S** asked about treatments that are available and show promise for people in their eighties and upwards. Specifically, are there some treatments that are considered too harsh? She has been treated with solo Rituxan, but it may not have been successful and she likely will need more treatment.

**Grete C** offered her opinion that physiological age is more important than chronological age. Other factors such as nutritional support, social support, and the medications one takes are important. The same treatments prescribed for younger patients may be appropriate for older patients, but with lower doses, fewer treatment days per cycle, and using fewer drugs in combination than is the standard. Dr. Treon has designated bendamustine and Rituxan (and also chlorambucil) suitable for older patients in the following publication: <http://www.bloodjournal.org/content/126/6/721?sso-checked=true> Dr. Véronique Leblond addresses the question in another article: [nature.com/leu/journal/v27/n4/full/leu201336a.html](http://nature.com/leu/journal/v27/n4/full/leu201336a.html)

Once again, this column covers only a small sampling of the topics and postings continuing daily. Everyone is invited to join IWMF-Talk and participate. All comments and questions are welcome. Many join just to “lurk and learn” and then find that they have something to contribute or a question to ask. We are all here to help and we welcome your questions and comments!

## IWMF DIRECTORY of PHYSICIANS: UPDATE

The IWMF DIRECTORY OF WM PHYSICIANS lists by country and city the names and contact information of oncologists and hematologists who are experienced in the treatment of Waldenstrom's macroglobulinemia.

All doctors included in the Directory are available for consultation with both patients and other physicians regarding the diagnosis, care, and treatment of WM.

Currently the Directory gives the names and contact information for 77 WM physicians within 13 countries.

China (Beijing and Shanghai) and the Netherlands (Amsterdam and Utrecht) are recent additions to the Directory, and there are some newly added physicians in the European listings.

Whether you are newly-diagnosed or an established WM patient, when you need a second opinion or consultation with a WM specialist be sure to check out the Directory of WM Physicians at:

<http://www.iwmf.com/get-support/directory-wm-physicians>

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# THE NINTH INTERNATIONAL DOCTOR-PATIENT FORUM

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On Sunday, October 9, the day following the conclusion of IWWM9, the IWMF joined forces on this occasion with Hematon, the Dutch blood cancer organization, in sponsoring the Ninth International Doctor-Patient Forum. One hundred and seventy-two attendees, coming from Western and Eastern Europe, Central America, Australia, Canada, and the United States, filled the Koepelkerk Conference Hall of the Renaissance Hotel in Amsterdam to hear from world-class authorities on Waldenström's macroglobulinemia. The speakers at the International Forum had, over the previous days, presented reports on their own recent research at IWWM9. The focus of the International Forum, however, was to provide an audience of WM patients, caregivers, and family members with current information regarding this specific blood disease. The topics of the day included diagnosis, treatment considerations, disorders related to WM, understanding the genetics involved, and patient self-care. The accompanying graphic images were projected in the auditorium on two screens, one in Dutch and the other in English.

Following a warm welcome by Moderator of the Proceedings Dr. Marie José Kersten of the University of Amsterdam, there were introductory remarks by Hans Scheurer, Board Member of Hematon, IWMF President Carl Harrington, and Dr. Guy Sherwood, IWMF Vice President for Research, who outlined the goals and the progress of the Strategic Research Roadmap initiative undertaken by the IWMF in collaboration with the Leukemia & Lymphoma Society.



*The Ninth International, cont. on page 24*





*Speakers and organizers of the Ninth International Patient-Doctor Forum: From left to right: Guy Sherwood, MD, IWMF; Ramon Garcia-Sanz, MD, Spain; Robert Kyle, MD, Mayo Clinic; Elena Malunis, IWMF; Monique Minnema, MD, the Netherlands; Marie José Kersten, MD, the Netherlands; Zachary Hunter, PhD, Dana-Farber Cancer Institute; Toni Dubeau, Nurse Practitioner, Dana-Farber Cancer Institute; Hans Scheurer, Hematon, the Netherlands; Jorge Castillo, MD, Dana-Farber Cancer Institute; Carl Harrington, IWMF.*

*Photo courtesy of Roger Brown*

The program then rolled forward with:

Dr. Ramon Garcia-Sanz, University of Salamanca, Spain (diagnostics and treatments); Dr. Robert Kyle, the Mayo Clinic, US (predispositions to WM);

Dr. Zachary Hunter, Dana-Farber Cancer Institute, (genetics and genomics of WM);

Dr. Monique Minnema, University Medical Center, Utrecht, the Netherlands, and Dr. Josephine Vos, St. Antonius Hospital, NL (disease co-morbidities).

The break for luncheon provided an opportunity to make new acquaintances and to relax and appreciate the paintings hanging in the Conference Hall (see photos).



The afternoon session featured:

Dr. Jorge Castillo, Dana-Farber Cancer Institute (treatment decisions);

Dr. Marie José Kersten, University of Amsterdam, NL (relapsed or refractory WM);

Toni Dubeau, RN/NP, Dana-Farber Cancer Institute (self-management of WM).

A quick break next and then the send-off: Ask the Doctor with Dr. Kyle at the podium and a lively panel of physicians at the ready to respond. Dr. Castillo, Dr. Hunter, Dr. Kersten, Dr. Minnema, and Dr. Vos participated.







Attendees departed from the Koepelkerk Conference Hall with much to reflect upon following the very informative Ninth International Doctor-Patient Forum.

The presentations from the Ninth International Doctor-Patient Forum are available in English on [iwmf.com](http://iwmf.com)

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# INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

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## FRANCE

Waldenström France held its annual meeting in the enchanting Musée des Arts Forains, Paris, on October 1. More than 80 patients, spouses, family members, and friends attended the meeting. Two sessions took place, the first led by Professor Véronique Leblond, who spoke in a general way about the disease Waldenström's macroglobulinemia, the second by Professor Jean-Paul Fermand on the more specific topic of amyloidosis. The meeting was followed by two visits to the museum. Everyone was truly amazed by the beauty and charm of the rooms.

Nothing can be done in France without a good meal, and so the day was completed with a dinner in a restaurant near the museum.

**Patrice Ostermann, Waldenström France, reporting.**

*The Musée des Arts Forains was certainly a unique venue for a WM meeting. Have a look!*

[http://www.arts-forains.com/index\\_anglais.php](http://www.arts-forains.com/index_anglais.php).

## GERMANY

The German Waldenström Support Group organized by Leukaemihilfe Rhein Main (LHRM) meets every two years, this year holding its two-day Symposium on September 10 and 11 in Darmstadt, Germany. More than 60 patients and caregivers from all over Germany and Switzerland – one third were newcomers – had the chance to submit questions ahead of the meeting. The presenters were Professor Kai Uwe Chow of the outpatient cancer center Schaubstrasse in Frankfurt and Professor Georg Hess of Gutenberg University Hospital Mainz. Both physicians received praise from the participants for their detailed presentations.

The presentations were recorded and can be viewed on the LHRM website:

<http://www.leukaemihilfe-rhein-main.de>

We regretfully report the death of Hans Erich Kiefer. Hans Erich was for many years in charge of the WM Group within LHRM. In his memory, a number of this year's participants agreed to volunteer more actively on behalf of the WM Support Group.

**Anita Waldmann, LHRM, reporting.**

## CANADA

On Friday November 11 we held our Fifth Bi-annual WM Fundraiser at the Arta Gallery in the Distillery District of downtown Toronto. The 94 guests enjoyed an evening of music provided by Thin City, and we danced the night away. Gourmet food stations and tasting platters kept our energy up, and our guests took great interest in the silent auction, the focus of the evening. With over 47 items up for auction,



*The Fifth Bi-annual WM Fundraiser held by WMFC attracted a lively crowd of 94 participants (including Drs. Chen, Hunter, and Castillo who were on the program for the following morning, see page 29) at the Arta Gallery in the Distillery District of downtown Toronto. Bidding was lively, and auction proceeds plus donations combined to total nearly \$40,000.*

including theatre tickets, hockey tickets, paintings, a Nepresso coffee machine, I-Pads, beautiful quilts – and so much more – the bidding was tense.

We were also presented with a cheque for \$28,670 from Rebecca Hinchcliffe, who held a fundraiser in support of WM this past July. Along with a donation from Shelby Knowlton, who also donated \$3,800 from a fundraiser she did in honour of her father, Michael Knowlton, we raised over \$39,470 for WM research.

We thank all those who came out to support us that evening and especially those who then attended our WMFC Educational Forum bright and early the next morning at The Royal York Hotel.

**Arlene Hinchcliffe, President, WMCF, reporting.**

## UNITED KINGDOM

Since the last *Torch*, things have become even busier. The first NICE (the UK health gatekeeper) funding meeting for ibrutinib in relapsed WM resulted in provisional refusal, accepting our WMUK evidence, plus that from Dr. Shirley D'Sa and Dr. Roger Owen as experts, but still not funding it. The meeting pack alone was 934 pages long! Our second meeting in November was strengthened by some of the results flowing from IWWM9, and we hopefully await a more positive result, as do the indications for CLL and Mantle Cell.

*(Update as the Torch goes to press: NICE has given approval to fund ibrutinib in relapsed CLL.)*

Meanwhile, we fought a bitter battle with the National Health Service (NHS) to restore stem cell transplantation, which

*International Scene, cont. on page 27*





Roger's birthday in Chingford.



Participants in the Bake4Rory held at the BBC.

ground to a halt in August due to a value for money reassessment fiasco. Some 14 transplants are carried out annually in the UK, mostly autologous with the patient's own cells. Not only was this a blow, but also patients being prepared for their transplants faced cancellation of their procedures. **Sandra Redshaw** and **Harriet Scorer**, with WMUK support, had to bravely campaign in the press, on TV, and in Parliament, where a petition rapidly attracted 12,000 signatures, meaning the government had to respond. This resulted in their transplants going ahead, but the main funding issue has still not been resolved at time of writing and we continue to campaign.

In early September we had a delightful garden party meeting at short notice in Chingford to coincide with my birthday, with 26 patients and carers, lots of cake, and many glasses of wine.

In October a large UK contingent went to IWWM9 in Amsterdam, with some 14 UK doctors involved in delivering papers or in the poster sessions, including one for the Rory Morrison Registry, and on that Sunday 25 patients and carers attended the International Doctor-Patient Forum generously sponsored by the IWMF and Hematon. It was particularly gratifying to see Dr. Roger Owen of Leeds receive the Jan Waldenström Award at the closing ceremony of IWWM9 for his services to WM, mainly through his extensive work in the pathology of the disease.

In the New Year we should see some more UK clinical trials with a multi-center BGB-3111 trial of this second generation BTK inhibitor, whilst it seems that the results from the acalabrutinib trial, ACP-196 (another BTK inhibitor) with some 60 UK participants, indicate that Astra Zeneca is looking at applying for regulatory approval in the USA in the first quarter of 2017.

There have been a number of notable fundraising events in autumn, but the highest profile was the fourth *Bake4Rory*, held at the BBC by Rory Morrison's colleagues. This event raised £4,000 towards the WM Registry, some half of the annual maintenance cost.

We are finalizing a late spring doctor-patient meeting at Oxford, and details should be available on our website by the time you read this. If you don't already receive our e-newsletter, subscribe on our website and join the WMUK community.

**Roger Brown, WMUK, reporting.**

## AUSTRALIA

### WMozzies WhiMSICAL CART-WHEEL Presentations

The WMozzies WhiMSICAL CART-WHEEL research study has been presented three times since its June launch.

- Sydney Leukaemia Foundation WM patient support meeting on October 19.
- Cancer Institute NSW Conference Innovation in Cancer Treatment in Sydney on September 16.
- Amsterdam at the International Doctor-Patient Forum on WM on October 9.

In Amsterdam at the International Doctor-Patient Forum, IWMF President Carl Harrington hosted a special briefing on the WhiMSICAL study for international WM leaders from the US, UK, the Netherlands, Germany, and Greece. WhiMSICAL Principal Investigators Associate Professor Judith Trotman and Dr. Ibrahim Tohidi-Esfahani led the presentation and responded to questions.

The presentation provided an overview of WhiMSICAL covering key differences of WhiMSICAL with the IWMF database. WhiMSICAL has established a robust ethically-approved WM data-collection platform via CART-WHEEL.org. WhiMSICAL has demonstrated the feasibility of generating patient-derived data with excellent recruitment since June. Ongoing activities involve patient data updates, expanded recruitment through the broader support of WM clinicians internationally, and the promotion of WhiMSICAL by the IWMF and its national affiliates. A significant increase in WhiMSICAL data is anticipated in coming years. The breadth of information gathered will expand knowledge of the range of presentations and treatment experiences of patients with WM. This will complement the depth of data derived from clinical trials and site-based registries. Demonstration of

any treatment disparities, coupled with information regarding treatment efficacy, may facilitate access to subsidised novel therapies.



*Panelists at the WM patient education meeting sponsored by the Leukaemia Foundation included Dr. Steven Treon, who was visiting Australia in the role of international speaker at the annual scientific meeting of the Haematology Society of Australia and New Zealand. To the right of Dr. Treon are: Associate Professor Dipti Talaulikar, Dr. Ibrahim Tohidi-Esfahani, Associate Professor Judith Trotman, and Andrew Warden representing the WMozzies.*

### **Melbourne Meeting with Dr. Steven Treon**

Dr. Steven Treon spoke at a WM patient education meeting at the Melbourne Convention and Exhibition Centre on November 15, organised by the Leukaemia Foundation. Dr. Treon was in Australia as an international speaker at the annual scientific meeting of the Haematology Society of Australia and New Zealand. On this occasion, WMozzies history was repeated. On his last visit to Australia in 2005, Dr. Treon was at the WMozzies inaugural meeting organised by the IWMF where he was one of “big three” WM expert speakers at the International Haematology workshop in Sydney.

Dr. Treon’s presentation this time was on the WM international perspective. Highlights of his address included latest international consensus on WM treatments and focus of ongoing WM research. Professor Miles Prince’s following presentation was on the WM Australian perspective. He spoke about the recent publication of the Australian clinical practice guideline for WM treatment. Important points highlighted by Professor Prince included:

- Treatment recommendations in Australia differ from those of international guidelines with a reduced emphasis on bortezomib, ibrutinib, and other newer agents due to limited access to Pharmaceutical Benefits Scheme (PBS) subsidised drugs for the treatment of WM.

- Bortezomib and ibrutinib are not yet available on PBS for the treatment of WM.
- Bendamustine, although approved on the PBS for *first line* treatment of indolent NHL (iNHL), is not reimbursed for patients with relapsed or refractory disease.
- Rituximab has been PBS listed for the relapsed or refractory setting, and access has been recently expanded for CD20 positive low-grade lymphomas in the frontline setting.

The panel session included Dr. Treon, Professor Prince, Associate Professors Judith Trotman and Dipti Talaulikar, and Dr. Tohidi-Esfahani. The panel answered submitted questions as well as questions from attendees. A number of questions related to clinical trials with ibrutinib. Steven Treon and Judith Trotman, answered these questions with great authority.

Co-Principal Investigator Dr. Tohidi-Esfahani gave a presentation on WhiMSICAL Research Study. His presentation is available for viewing on YouTube via the link on the WMozzies website in the WhiMSICAL study section.

### **Australian Guideline on WM Treatment**

The Australian WM Treatment Guideline was released in November. It is a consensus established by the Australian medical scientific advisory group (MSAG) to the Myeloma Foundation Australia. MSAG consists of a panel of 24 haematologists across Australia, as well as local experts. The panel includes 7 members who are in IWMF Directory of Australian WM doctors. They represent 24 Australian organisations covering university departments of haematology, clinical haematology and BMT, institutes of medical research, faculties of medicine, health, nursing, medical and health sciences, and medical schools. Professor Prince is chair of MSAG. The equal contributor authors of the guideline are Associate Professors Talaulikar and Constantine S. Tam. The 24 panel members represent all states and territories. The Australian WM treatment guideline is included in the downloadable publications section of the IWMF website.

The guideline includes tables covering treatment indications, recommended workup, and differential diagnosis of WM, International Workshop response criteria, and doses and schedules of frontline regimens for WM. The section on drug access in Australia highlights that treatment recommendations in Australia differ from those of international guidelines as mentioned above.

**Andrew Warden, WMozzies, reporting.**



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# WMFC EDUCATIONAL FORUM 2016

BY RON TERNOWAY, NOVA SCOTIA SUPPORT GROUP CO-LEADER

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*The audience at The Royal York Hotel was eager and intent on absorbing as much as possible about all the latest developments concerning WM and treatment options.*

Bleary-eyed after a late night at the fabulous Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) fundraiser the night before, more than 75 Canadian WM patients and caregivers gathered 18 floors above downtown Toronto for the sixth WMFC Educational Forum on November 12.

A smiling, welcoming WMFC President Arlene Hinchcliffe and her volunteer crew were models of efficiency and grace as they greeted and registered Ed Forum participants, then directed us to the sumptuous breakfast buffet. At promptly 9 am, Arlene welcomed us all, and the learning began in earnest.

First on the podium was Dr. Zachary Hunter from the Dana-Farber Cancer Institute (DFCI) in Boston (Dr. Hunter was also recipient of the prestigious Robert A. Kyle Award at the recent IWWM9 in Amsterdam, see page 1) with a crash course in Genetics 101, the WM version. Dr. Hunter's engaging, precise delivery was enhanced by clear and concise slides that led us from understanding DNA to cell division, genomes, and the significance of the now-famous MYD88 and CXCR4 mutations in choosing the best therapy to treat our disease.

Clinical experience has shown that the first-generation BTK inhibitor Imbruvica (ibrutinib) works best in WM patients who have the MYD88 mutation but **not** the CXCR4. Dr. Hunter shared news of an upcoming clinical trial of CXCR4

inhibitor ulocuplumab, which may improve the effectiveness of BTK inhibitors for those of us with CXCR4 mutations.

Next up was Dr. Christine Chen of Princess Margaret Cancer Centre in Toronto, one of Canada's leading WM specialists. Dr. Chen took us on a magical history tour entitled "The Evolving Paradigm of Therapy." She pointed out how, until recently, therapies for WM had always been hand-me-downs from more common lymphomas and leukemias. Starting in the 1980's with alkylating agents (cyclophosphamide, chlorambucil) and purine analogs (cladribine, fludarabine) through the 1997 innovation of the first monoclonal antibody, rituximab (Rituxan), alone or in combination with other therapies (CHOP-R, CVP-R, CP-R, DRC, BR), some other blood cancer patient always got the therapy before a Wally did.

In early 2016 Health Canada approved Imbruvica (ibrutinib) for use in all WM patients, but in November the pan-Canadian Oncology Drug Review (pCODR) board rejected a request for funding the drug through Canada's Medicare system. As a result, routine genetic testing of bone marrow for MYD88 and CXCR4 mutations is not done in Canada. It can, however, be selectively requested by Ontario hematologists and perhaps by those in other provinces.

The current first-line treatments for younger or fitter Canadian Wallies are bendamustine and rituximab (BR) or

*WMFC Educational Forum, cont. on page 30*



*Breaks in the program provided an opportunity for those attending to speak directly to the presenters. Here Dr. Castillo responds to questions.*

dexamethasone, rituximab and cyclophosphamide (DRC) followed by 2 years of rituximab maintenance. For older or debilitated patients, chlorambucil or solo rituximab is the choice. In either case, re-treatment with the initial therapy is considered if the time to relapse is more than one year. For the moment, Imbruvica is only available to Canadian WM patients with gold-plated health insurance plans or very deep pockets – or those on a clinical trial. At the time of this report, new applications to Janssen Canada's You&I compassionate care funding programme for WM would be accepted until December 31, 2016.

After coffee break, Dr. Jorge Castillo brought his extraordinary bedside manner to the stage as he addressed "Novel Approaches in WM." A worthy successor to Dr. Stephen Treon as head clinician for WM patients at Dana Farber, Dr. Castillo's empathy, sense of humour, and profound understanding of our shared malady was apparent to all.

Dr. Castillo highlighted the significance of our nearly-universal MYD88 mutation as a key to the success of Imbruvica (ibrutinib) therapy and shared results of the Phase II clinical trial which led to FDA and Health Canada approval of the drug for the treatment of WM.

We also learned about ongoing clinical trials at DFCL, including:

- Ixazomib, dexamethasone, and rituximab in treatment-naïve patients.
- Ibrutinib for treatment-naïve patients – a few spots still available at this writing.
- BCL2 inhibitor venetoclax for previously treated patients.

Coming soon – trials of anti-CD38 monoclonal antibodies, CXCR4 inhibitors, and MYD88 blockers.

After lunch, IWMF Research Committee Chairman Dr. Guy Sherwood presented details of current IWMF and WMFC-sponsored research projects. The IWMF and WMFC have raised more than \$10 million for WM research and have also instituted the Young Investigator Awards, where up-and-coming researchers are sponsored to attend International WM Workshops. Nine young investigators were sponsored for IWMF9 in Amsterdam this year (see page 5).

Lori Halton, a registered dietitian with Cleveland Clinic Canada's Executive Health program, presented valuable advice on proper nutrition while undergoing chemotherapy. She stressed the importance of maintaining body weight in the face of

loss of appetite and digestive problems. Lori recommended increased intake of calories, protein, and fluids and reminded us to avoid antioxidant supplements (Vitamin A, C, E, selenium and zinc) while on chemotherapy. Plenty of fruits and vegetables provide phytochemicals that enhance the body's ability to heal. High-nutrition drinks like Boost and Ensure may be used to bolster calorie and protein intake.

Finally, Robin Markowitz, CEO of Lymphoma Canada, reviewed the pCODR process and their decision to reject the application for the funding of Imbruvica for WM in Canada. The Expert Review Committee, composed of oncologists, physicians, pharmacists, economists, ethicists and patients, concluded that the limited clinical evidence as to effectiveness of Imbruvica, the availability of other therapies, and the high cost of the drug were key factors in their decision. These concerns outweighed very strong WM patient input as to the effectiveness, ease of oral therapy at home, and improved quality life brought about by Imbruvica.

Two Ask the Doctor sessions complemented the uniformly high quality of the presentations. As the sun set slowly in the west, our heads spinning from information overload and our lives enriched by contact with fellow travellers, seven dozen Wallie Canucks headed home counting our blessings.

WMFC 2017 Ed Forum in Halifax, anyone?



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# SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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*Members of the Northern California Support Group at their recent meeting.*

## **Please note!**

Contact information for all Support Groups is found on *iwmf.com* under GET SUPPORT.

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

## **CALIFORNIA**

### *Northern California*

Laura Ellingson, Professor of Communication at Santa Clara University, spoke at the October meeting held at Cancer CAREpoint in San Jose, CA. The topic of her presentation was “Communicating with Your Doctor.” Her research focuses on communication in clinics and hospitals. She is currently completing a study that uses both social science and art to explore long-term cancer survivorship. Dr. Ellingson discussed how to prepare for medical appointments and how to use a partnership approach in order to meet the patient’s needs and to make the most of the physician’s time. She included practical ideas as well as suggestions for how to think about priorities and about the quality of life desired at each stage of the cancer journey. The following key points were touched upon as suggestions for doctor appointments: aim for partnership; be prepared for your visit; communicate priorities; don’t be bashful; express yourself; finalize plans including next steps. After the meeting refreshments were enjoyed by all.



*Professor Ellingson made a very insightful presentation that included many tips and practical suggestions, especially for patients who intend to communicate effectively with their doctors and share in management of their disease.*

## **COLORADO AND WYOMING**

On Saturday, October 29, more than 47 people met for a light lunch sponsored by the Leukemia & Lymphoma Society (LLS) and a great informative presentation by Dr. Jeffrey Matous, Medical Director at the Colorado Blood Cancer Institute and Clinical Professor of Medicine at the University of Colorado. Dr. Matous gave an overview of WM, followed

*Support Group News, cont. on page 32*





*Chicago Support Group Leader Don Brown at the podium during the group's recent meeting, which coincided with the annual Lymphoma Research Foundation's Educational Forum and was held in the Palmer House Hotel, a landmark of downtown Chicago.*



*The annual summer picnic of the Chicago Support Group is traditionally a well-attended event, and this year was no exception.*

by a recap of IWWM9 (see page 1) held in Amsterdam, which he had attended earlier in October. Not only was his talk very interesting, but questions were allowed during and after his talk, creating a relaxed, informal sharing of information. His “takeaways” were: how patients are feeling dictates treatment, not high IgM numbers; and all patients should get current flu and pneumonia shots. The hot topic of the day was the high cost of ibrutinib and similar drugs.

## ILLINOIS

### *Chicago Area/SE Wisconsin*

Since the last roundup, the group has been busy, meeting for its annual picnic in August and again in the fall. The picnic was at **Sara and Mike Thran's** home. Sara is a member of the program committee and a gracious hostess. The picnic as usual created an atmosphere of friendly fellowship. For the first time, this fall the meeting took place during the annual Lymphoma Research Foundation's Educational Forum held at the Palmer House Hotel in downtown Chicago. Both Dr. Steven Treon of Dana-Farber Cancer Institute and Dr. Stephen Ansell of Mayo Clinic Rochester spoke at the weekend-long conference. Dr. Treon led Saturday and Sunday breakout sessions on the latest treatments and research relating to Waldenstrom's. Despite the fact that Wallies represent a small minority of total lymphoma patients, about 50 WMers (out of a total of 375 registrants at the conference) came to the Forum, adding up to more than 10% of the attendees. Dr. Treon mentioned that WM-specific research is now breaking new ground for all lymphomas. Jesse Brown, event coordinator for the LRF (and no relation to **Don Brown**, the support group's facilitator), arranged for the group to hold its own meeting at the venue on Saturday evening. After introducing some new Waldenstrom's patients from around the US and the local area, Carl Harrington, IWWM President, summarized the IWWM-LLS Strategic Research Roadmap. Chicago Cubs fans did not lose sight of the history being made at Wrigley Field during the LRF Forum. Despite losing their hometown games, the Cubs managed to go on to win in seven games at Cleveland and to break a historic 108-year drought! The spring meeting will be at the usual location, Lutheran General Hospital in Park Ridge, IL.

## INDIANA

A smaller-than-usual group met in early November at the LLS office in Indianapolis. Due to technical difficulties, the planned program – to view Dr. Jorge Castillo's presentation to the Philadelphia support group – was aborted. However, the group had so much to talk about that a great round table discussion ensued, focusing on treatment options and side effects. One member said that the reason he came to the meeting was to participate in a discussion! Later, an e-mail went out to all members with instructions on how to access Dr. Castillo's presentation.

## NEW YORK

### *New York City*

On a beautiful November afternoon, 28 energetic and talkative members met at the Mahon Center at Weill-Cornell Medicine for a spirited discussion about such topics as: new drugs, for example venetoclax/ABT-199, which one member is taking in a trial and is doing encouragingly well; side effects; dosage levels (and who decides – the patient, the doctor, or both?); doctors who keep patients waiting for hours; frequency of check-ups; which blood tests are necessary to get a full picture of health with WM; and more. It was a similar range of pertinent, perennial questions to those found on IWWMF-Talk. This meeting was the first in a long time without a “newbie” in need of information and empathetic support. Instead, it was just the usual gang of veterans who continue to enjoy keeping up with each other and find value in the meetings.

### *Eastern NY and Western New England*

In August our group enjoyed our annual summer picnic. As each member brought food to share, we satisfied our appetites and enjoyed the conversations. In mid-November the group met as usual at the American Cancer Society's Hope Club in Latham, NY. Two members were the featured presenters, each discussing a salient portion of their WM journey. **Leslie Neustadt** facilitated a session devoted to bendamustine at the 2016 IWWMF Educational Forum. The drug continues to be prescribed as a frontline therapy for WM. Leslie gave the group some background on bendamustine and discussed the side effects and efficacy of the treatment. Since she is a LIFELINE contact for both bendamustine and amyloidosis, Leslie also described the issues typically raised by callers to the LIFELINE and how she helps guide them to make informed decisions about treatment. The second speaker, **Peter Skinner**, who is now part of the IWWMF planning committee for the 2017 Educational Forum, shared details of his experience in a Dana-Farber Cancer Institute clinical trial. In addition, he discussed new drugs currently in clinical trials and then launched into news from the Providence, RI, Ed Forum and the IWWM9 International Doctor-Patient Forum in Amsterdam. Peter has CLL as well as WM and his clinical trial (IDR or ixazomib/dexamethasone/rituximab) has meant excellent results for him. The group broke for a bag lunch and continued talking, exchanging information, and making plans for future programs.

### *Rochester, Western, and Central NY*

The upstate NY group is small, about 8-10 active members. At the last gathering, long-time leader, **Stephen French**, asked if **Lynn Milliman** would take over as group facilitator. Here Lynn introduces herself in her own words: “My name is Lynn Milliman and I live in Penfield, NY. I was diagnosed with WM in 2013 and remain on ‘watch and wait.’ I am being followed by a hematologist at the Wilmot Cancer Center,





More than 20 members of the Philadelphia Support Group met at the home of leader Lisa Wise for their annual autumn meeting. The lively conversation included exchange of personal news and much useful information. The table chez Wise was spread with abundant seasonal fare, including the house specialty, vegetarian chili – see page 36 for the recipe.

Strong Memorial Hospital, in Rochester. My husband and I attended the 2016 IWFM Educational Forum in Providence, RI. It was extremely educational and inspiring. I have been a member of the local support group for about a year and a half. The group gathers a few times a year at a local restaurant, and I look forward to continuing the tradition. With the help of the more experienced members, I hope to expand the opportunity to disseminate the latest information on WM research through printed materials, CDs, and guest speakers.”

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

Two new Wallies and their caregivers were warmly welcomed to the mid-summer get-together at the Cuyahoga County Branch Library in North Royalton, OH. Members offered them encouragement and support, sharing their stories of hope, from treatment to remission to getting good care for WM. By group consensus, the group viewed Dr. Stephen Ansell’s presentation from the 2016 Ed Forum, “IWFM Research Roadmap Overview and Bone Marrow Tumor Microenvironment.” Dr. Ansell’s hopeful message of new advances in research and treatment created an optimistic spirit among the group. As always, an abundant array of snacks and beverages were available to contribute to an enjoyable afternoon. Then in the fall, on a warm, late-October afternoon, WMers from as far as Cleveland met at the home of **Marcia** and **Glenn Klepac** in Pittsburgh, PA. The guest speaker, Theresa Brown, BSN,

RN, home hospice nurse, and author, created a spirited, open discussion following her presentation of “What Nurses Do.” Theresa is the author of the *New York Times* bestseller *The Shift: One Nurse, Twelve Hours, Four Patients’ Lives*, a moving account of the joys and challenges that Theresa experienced during her shift on an oncology floor. The discussion laid the groundwork for members to share personal experiences from a patient and healthcare professional perspective: two are retired nurses and another is a retired physician. Improved communication between doctors and nurses was highlighted as a key target for better patient care. Refreshments followed – salad, fruit, sandwich selections, and two fabulous cheesecake options by our dessert chef, **Shari Hall**. Members chatted to catch up on events in their personal lives including their latest WM updates.

#### **PENNSYLVANIA Philadelphia**

When the clocks change, the days shorten, and the world feels a little shaken up. **Lisa Wise**, the area’s Support Group Co-Leader, offers a cure: gather together with good friends to enjoy good food in a warm, welcoming atmosphere that builds connections, heals the heart, and helps Wallies understand they are not alone on their WM journeys. In November, Lisa collected more than 20 members together for what is now an annual autumn gathering. The centerpiece of the generous

*Support Group News, cont. on page 35*





*Dr. Jorge Castillo and members of the Northern Virginia support group who gathered this summer to participate in the two-hour program during which Dr. Castillo spoke on recent advancements in the management of WM. He generously replied to questions raised by his remarks and was also available to those attendees who wished to ask about specific disease-related issues.*

buffet was her Vegetarian Chili (see her recipe in Cook's Happy Hour page 36), flanked by honey corn bread, hot apple cider, spinach salad, fresh fruit, and sweets. But the rich and stimulating group discussion and member "catch up" session provided real nurturing as well. Participants shared health updates, exchanged helpful online resources, explained complex treatment choices, and discussed how to meet the challenges of the high cost of cancer medications, medical insurance coverage, and advocacy efforts around parity issues. Many expressed interest in attending the May 2017 IWWMF Ed Forum in Phoenix, AZ. The group collectively explored possible improvements to the meeting format and e-mail communications sent between quarterly meetings. An online survey for members to "rate" their interest in future meeting topics (such as the effect of a cancer diagnosis on career, retirement, estate planning, etc.) is in the planning stages. The power of sharing stories and experiences with a group of folks who understand because they, too, travel the same path, is not to be underestimated. A highlight of this meeting was the gift of a small plant for each member. A newly diagnosed patient – who happens to be a horticultural therapist by profession – brought the plants to act as a symbol of hope and optimism. It was an outstanding gathering, and everyone really had a ball together.

### WASHINGTON

In the fall, the group hosted its big, annual fall meeting at the Fred Hutchinson Cancer Research Center. This year about 70 people attended (including some from out-of-state) to hear several presentations. Dr. Andrew Cowan covered

"What Does a WM Diagnosis Mean for You?" Dr. Ed Libby discussed "Expect the Unexpected" and "Treatments and Trials," and Charlie Pieterick, Advance Registered Nurse Practitioner (ARNP), spoke about "Finding Support with Palliative Care." As usual, the Q&A with Dr. Libby was lively and covered a wide range of WM-related topics with lots of useful information. All the presenters are with Seattle Cancer Care Alliance (SCCA, a union of Fred Hutchinson, University of Washington Medicine, and Seattle Children's). Dr. Libby is a very popular, local WM specialist. He had recently returned from the IWWM9 in Amsterdam, and he had some very interesting news about research and new drugs in the pipeline. The meeting was jointly sponsored by the IWWMF and SCCA.

### NORTHERN VIRGINIA/WASHINGTON DC/ WESTERN MARYLAND

Dr. Jorge Castillo of the Bing Center for WM at Dana-Farber Cancer Institute generously traveled to the area in July. He brought almost 60 WMers and caregivers up-to-date with his presentation: "The Latest Advancements in Waldenström's: A 2016 Update." He kindly addressed many questions throughout the two-hour program, elaborating on specific topics and relating them to the questioners' concerns, allowing all members of the group to benefit from hearing these extra details. Dr. Castillo lingered for one-on-one questions from patients, further addressing personal issues. Afterwards, grateful thanks flooded in to **Lu Kleppinger**, group leader, attesting to the delight and excitement caused by Dr. Castillo's hopeful news and personal attention.

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# COOKS' HAPPY HOUR

GUEST CURATED BY LISA WISE

PHILADELPHIA SUPPORT GROUP CO-LEADER

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*Lisa, the enthusiastic Philadelphia Support Group Co-Leader, clearly likes to cook and to bring people together around good food. Last year, she sent me this recipe which I've saved until now. The stew brims with vegetables and beans, some canned products for convenience, and a meat substitute. If processed soy is not your thing, feel free to substitute tofu or tempeh. And if meat is part of your diet, feel free to replace the meat substitute with some ground chuck. Herewith, I will turn the proceedings over to her. Penni*

Nothing beats coming in from the cold to a steaming hot bowl of chili with warm cornbread. Okay, sitting by a pool on a warm, sunny, summer day might beat it, but in these winter months, get your cozy on and enjoy a big bowl of veggie love. It may seem like the recipe takes a long time but it makes 12 generous portions and keeps well, covered and refrigerated, and disappears pretty quickly.

Heat some olive oil in a large (chose a very large one!), heavy pot over medium heat and sauté 1 or 2 medium, yellow onions until soft and transparent. Add some finely chopped garlic (the amount depends on you, try 3 large cloves), 1/2 or 1 pound sliced mushrooms (Tip: buy pre-sliced to save time. I use a mix of cremini, baby portobellos, and oyster mushrooms when I can find them. Otherwise, button mushrooms are fine.), and lots of coarsely chopped vegetables such as green, red, and yellow peppers; zucchini; cubed yams or pumpkin; carrots; parsnips; turnips and rutabagas (anything you

love!). Cook over medium heat until the veggies soften. Stir regularly to prevent sticking and add a little water if needed.

Add 2 (16-ounce) cans of Heinz Vegetarian baked beans, 1 or 2 (14.7-ounce) cans of Amy's Organic Vegetarian Chili, and 1 (28-ounce) can of Hunt's chopped tomatoes. Bring to a boil over high heat, then lower the heat to maintain a simmer, and cook, uncovered, to blend all the ingredients and until the vegetables are thoroughly cooked.

Heat a small amount of olive oil in a skillet and sauté 1 (12-ounce) package of soy-based "ground beef" over medium heat until browned. (Note: I like to use Morningstar Farms Meal Starter Griller Crumble or Lightlife Smart Meatless Original Crumbles, two great sources of meatless protein.) Add a good dose of your favorite bottled BBQ sauce and cook until melded and hot throughout. Add this to the vegetable mix, stir well, and continue to simmer gently. Total simmering time will be about 2 hours.

Season with chili powder, cumin, brown sugar, basil and other herbs, fresh or dried (anything you like), and salt and pepper. Make sure to taste before seasoning. Continue to simmer until all the ingredients come together nicely and the aroma makes you hungry.

Serve topped with sliced scallions, shredded mozzarella, Greek yogurt or light sour cream, and hot sauce.

*Our motto: Eat Well to Stay Well*

*WALLY and WINNIE, WM Model Mice by Linda Pochmerski*



Phoenix, surrounded by radiant red rocks, blue sky, and golden sunshine, is the cosmopolitan city of Arizona that will host the 2017 Educational Forum.

**SINCE AUGUST 2016, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL  
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

**Sandra Adamson**  
John & Dee Bianucci  
Patricia Bonk  
Robert & Helen Floyd  
Pattie Foley-Munoz  
Geogene Harris

**Arlene Antilla**  
Gayle Backmeyer

**Marvin H. Arenson**  
Beth Levin

**Marcel Augereau**  
Waldenstrom France

**Dr. John Austin**  
Paula Austin

**Zachary Bartz**  
Harvey A. Bartz

**Freddy Bastin**  
Nicole Bastin

**Eric Birmingham**  
Joan Birmingham

**Gayle Clites**  
Roy & Fran Clites

**Robert M. Coulbourn, III**  
Bennett Wethered

**Rachel Culver**  
Anonymous

**Mildred Davis**  
Anonymous  
Ken & Barbara Hand  
Georgene Harris

**Eleanor M. Dowd**  
James Dowd

**Ron Draftz**  
Hubert C. Edfors  
Suzanne Herms

**Daniel Drexler**  
Cathy Drexler  
Wade Mueller

**Kenneth Ewen**  
Penelope Ewen

**George Farrier**  
Margaret Farrier

**Jerry Fleming**  
Sally Stephens

**Amy Foster**  
Amy Foster Memorial

**Bruce WM Warrior Fox**  
Francine Fox

**Melvin Freedman**  
Muriel F. Goldberg

**Patrick Fulton**  
Jim & Carole Phillips

**Philip Gover**  
Joyce Gover

**Ann Gray**  
Boyd Burkholder

**Bob Greene**  
Ed Goldberg

**Alden Vincent Halloran**  
Nossaman LLP

**Mary Lou Haffner**  
Pat & Stan Czyson

**Robert Hakes**  
Cathy Hakes

**Donald L. Hann**  
Cheryl Hann  
Jamie Hilker  
The Hoy Family

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