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DOCTOR ON CALL: GWEN L. NICHOLS, M.D.

CLINICAL TRIALS – SHOULD YOU PARTICIPATE?



Dr. Gwen Nichols

Gwen L. Nichols, M.D., is currently the Oncology Site Head of the Roche Translational Clinical Research Center at Hoffman-LaRoche. In this capacity she works to develop new medications for oncology indications, translating them from the laboratory into human clinical trials.

Dr. Nichols trained in internal medicine at the University of Chicago and completed post-doctoral research and a hematology-oncology fellowship at Memorial Sloan-Kettering, where she served as an attending physician on the leukemia service. Prior to joining Hoffmann-La Roche in 2007, Dr. Nichols was the director of the hematologic malignancies program at Columbia University in New York. In this capacity, she managed laboratory research and developed clinical trials focused on hematologic malignancies. While at Columbia, she also maintained an active clinical practice and served as Assistant Dean of Students for Columbia University's College of Physicians and Surgeons. Dr. Nichols was voted "Physician of the Year" at Columbia, as well as being chosen for the Humanism in Medicine Award.

Dr. Nichols is a member of the IWMF Scientific Advisory Committee and has presented at several IWMF Educational Forums.

The subject of clinical trials has been featured extensively in the recent press. A 2013 article in the *New York Times Sunday Review* entitled "Do Clinical Trials Work?" raised questions about the long time that drug development takes, the costs, and the measurable benefit of clinical trials as they are currently performed. A recent announcement of the Blood Cancer Research Partnership (BCRP) between the Leukemia & Lymphoma Society and Dana-Farber Cancer Institute has raised many hopes as well as questions about expanding access to clinical trials in community settings. Few would disagree that newly developed, more effective medicines need to get to the right patients faster and less expensively. The formula for doing this more efficiently, without compromising patient safety, is a work in progress.

For individuals deciding whether or not to participate in a clinical trial, there is a host of conflicting information. It is not always clear what the purpose of a given trial may be, what a participant should expect, and who really stands to benefit from the patient's participation. While there are no "one-size fits all" answers to the question "Should you participate?" a clear understanding of the questions and complexities involved can help you obtain the necessary information to make an informed decision.

HOW DOES A DRUG GET DEVELOPED?

The long process of developing a new medicine often begins when a laboratory has either targeted a particular molecular pathway or a disease or is screening compounds. If, in the course of these investigations, an activity is discovered that may be relevant against cancer *in vitro* (in

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Doctor on Call, cont. from page 1

the test tube), a variety of cancer models can be explored to evaluate the innovation's therapeutic potential. This can be accomplished in an academic lab or within a company.

It may take years to understand the mechanism of action in cell lines and in animal tumors before a particular discovery can be turned into a drug. This process often involves extensive chemistry and formulation work so that the agent can be produced as a pill or a liquid that is safe for humans, in quantities suitable for further testing. Typically, toxicology testing is the next step. Very specific safety studies (depending on the type of agent) in animal models are required before a drug can be submitted to regulatory agencies for required approvals to allow studies in humans.

Next, an Investigational New Drug (IND) application is submitted to the health authorities which includes extensive documentation of how the drug will be produced and stored, the clinical plans for development, and how patient safety will be assured.

Phase 1 is generally an "Entry-Into-Human" trial. This is usually the first time any human has received the drug. Critical findings for Phase 1 are to understand the pharmacology of the new agent: how much drug to give, how it is metabolized, and how it should be dosed (both dosage amount and frequency) in patients. All this is accomplished with step-wise increments to learn about harmful side effects, as well as beneficial effects. In Phase 1 the goal is always to err on the side of safety, so the dose that initial study patients receive may not be the amount for the final or effective dose.

The studies start at doses well below the doses where side effects were seen in animals, as animals may not predict what is seen in humans. Dose testing in Phase 1 continues either to a maximum biological dose (where an effect is predicted to be seen) or to a maximum tolerated dose. Phase 1 trials increasingly are looking for effects of the drug in blood or tissues or through scans as the doses are increased. Patients participating in a Phase 1 trial must agree to the testing required for the study by signing an informed consent form. Overall, the amount of testing, the number of days at the clinic, and the requirements for biopsies and scans may be extensive in order to determine the best way to give the drug in the future.

Phase 2 trials often involve more patients. At this stage researchers analyze the drug's efficacy and safety in patients selected by disease characteristics. These trials may be performed in combination with or in comparison to a standard of care treatment. Phase 2 trials have specific eligibility criteria for selecting patients. Factors may include particular stages of a given disease, the number of prior treatments, general health

Doctor on Call, cont. on page 3



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characteristics, tumor biopsy, or pathologic characteristics. The number of patients and the studies being performed are based on the required level of statistical assurance to support reproducible findings that would demonstrate benefits superior to available treatments.

To participate in a Phase 2 trial, patients need to meet all the entry criteria to ensure that the study data is reliable. This can be frustrating, particularly if one's disease characteristics differ from the norm. For researchers there may also be a valid concern that highly selected populations may not adequately reflect the more general population of patients with a given condition. Novel ways to expand where Phase 2 trials can be performed may improve the success rate of Phase 2 studies and help in predicting success in Phase 3.

Phase 3 trials are based on Phase 2 data. They are chiefly designed to statistically demonstrate clinical benefit versus a standard treatment. Phase 3 trials involve more patients and an increased number of locations. Most Phase 3 trials are done in order for the drug to seek approval for marketing. Phase 3 trials are generally randomized and are often double-blinded. Randomization means that patients are assigned to a particular treatment by chance (the test treatment may or may not contain the new drug being tested). Double-blinded means that neither the patient nor the treating physician knows which treatment the patient is getting. Placebos are rare in oncology trials, but participants in a Phase 3 trial may get a standard of care drug that is also available for those with the same disease who are not participating in the trial.

Results of Phase 3 studies are presented to health authorities as part of a new drug application (NDA). Phase 3 trials often take years to perform. One reason is the large number of patients who need to participate. Another is that the endpoints of the study in oncology are frequently progression free survival or overall survival over a significant period of time. Thankfully, as treatments improve, median overall survival for many diseases is longer than in the past. But this poses a difficult question for drug development. Do we have to wait years to answer the question of benefit for patients based on survival or are there "surrogate" endpoints that will adequately predict what will happen years down the road? Researchers and regulatory authorities are carefully examining these questions for future drug development. It may seem obvious that shrinking of a tumor or lymph node would predict improvement in progression free survival or overall survival, but this is not always the case. Each particular disease must be examined for adequate markers of efficacy that can serve as reliable "surrogates" for helping patients live longer.

Lastly, you may hear about studies that fall outside of the typical Phases. These may involve pharmacology or new formulations of a drug, different dosing and schedules, or testing of biomarkers which predict activity; still others are simply conducted to learn more about the disease. These

trials may provide patients access to drugs when the patient doesn't fit the particular entry criteria for a randomized study.

Questions to ask your physician about participation in a clinical trial:

- What is the phase of the study and what is the goal or endpoint?
- How frequently will I need to be in the hospital/in the clinic for testing and what type of testing is required?
- If I fail to respond to the drug, does getting this treatment prevent me from getting other treatments?
- Does the science make sense?
- What is the likelihood that I will be helped by participation?
- Are there approved or standard therapies which make sense to use first?

Questions to ask yourself before participation in a clinical trial:

- Am I willing to have a biopsy or other studies (x-rays, blood work) required for participation?
- Am I ready to participate in order to help others in the future if this has only a small chance to work for me?
- Am I a person who believes in the scientific process?
- Am I willing to follow all of the elements of the research study, even if they are inconvenient?

SOME FREQUENTLY ASKED QUESTIONS

Why does drug development take so long?

The development process has a lot of safeguards to protect participants. Some complain that drug development isn't safe enough, that drug companies rush drugs through to approval, and that too many drugs get withdrawn from the market after they have been approved. It is a delicate balance between getting new medicines to patients, making sure the business of research and development is financially sound, and discovering rare (1/1,000 or 1 /100,000) but important side effects. This can take years. Companies often agree to post-marketing or Phase 4 evaluations for safety and efficacy precisely to learn about these rare but important side effects.

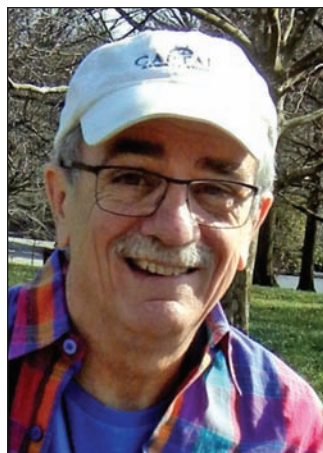
Why are many of the trials only in large research centers?

Determining a drug side effect compared to the effects due to underlying disease, other medical conditions, or other medicines can be a challenge, particularly in oncology patients. If an investigator is too conservative, the drug testing may be stopped before an effective dose is reached. If an investigator is too liberal with criteria, safety may be

Doctor on Call, cont. on page 40



PRESIDENT'S CORNER



Carl Harrington, President

We're celebrating! This special, full-color Fifteenth Anniversary Issue of the *Torch* shows how much we have to be grateful for in 2013 versus 1994 when Arnie Smokler started the first support group or 1998 when we were incorporated as the IWMF. In this issue, you'll get a sense of what life was like for the newly diagnosed Arnie Smokler and other extraordinary WM "pioneers." Through diligence and hard work, they effectively led WMers away from a time of ignorance and isolation toward a new era of understanding and awareness of our disease.

Among the articles in this *Torch*, IWMF President Emerita Judith May chronicles the history of the IWMF, Davell Hayes tells about getting the IWMF up and running, and Eugene Turner, an 18-year survivor and a living legend in the northern California support group, shares his WM experience from a time when prospects were bleak for a patient diagnosed with advanced disease. For these pioneers, the stakes were truly high. As Laurie Rude-Betts, who contributed to the article by Davell, comments, "They were fighting for their lives." Because they did, we are all so much better off!

How much better off?

- In 1994, Arnie Smokler started with a list of **21** patients from NORD (National Organization of Rare Diseases). Today, we have **6,307** members in **64** countries worldwide.
- In 1994, no one knew what the accurate estimate of life expectancy was for a WM patient. In 2006, when I was diagnosed, the IWMF website said **5-7 years from diagnosis**. Today we say **11.6 years from the start of treatment**. And this is now old data and not based on the current and upcoming treatments.
- Since 2000, the IWMF has invested over **\$6,300,000** into over **35** strategic research projects focused on

WM. Our Research Program has yielded tremendous results, as you will also read in this *Torch*, from WM cell lines, mouse models, and the identification of the MYD88 genetic mutation, results that benefit us all with more and better treatment options and longer, healthier lives. All made possible by the generosity of WMers like you.

- In 1998, we had **10** support groups in the US and **1** in the UK. Now we have over **75** support groups in the US, **7** in Canada, and **4** in the UK. Other groups or contacts are in Belgium, Greece, Denmark, Sweden, Norway, Iceland, Ireland, Germany, Finland, The Netherlands, France, Italy, Australia, Israel, India, and beyond.
- The first Ed Forum had **75** attendees. Our May 2013 Ed Forum in San Diego had nearly **250** attendees.

The numbers highlighted above don't come close to capturing our huge steps forward with our other education and support efforts, including the IWMF website iwmf.com, the *Torch*, our series of booklets, the Patient Database, IWMF Lifeline, IWMF-TALK, and more.

We've left the dark days behind, and now, thanks to advancing knowledge, we're in a new era for WMers everywhere. With the enormous research progress from MYD88 to the Breakthrough Therapy Designation from the FDA for ibrutinib, we're closer than ever to a cure.

Schedule time in 2014 to attend the following – you'll learn a great deal and you'll enjoy meeting your fellow WMers:

- The nineteenth annual IWMF Educational Forum in Tampa, Florida, at the Renaissance Tampa International Plaza Hotel from May 16 - 18.
- The Fifth International Waldenstrom's Patient Forum in London on August 17.

Why not channel some of that IWMF pioneer spirit yourself? If you haven't filled out your *Imagine a Cure* pledge card, do it and mail it in today. If you have, thank you! Please also consider volunteering your time and skills to the IWMF!

Anything is possible if we all work together. Just look what Arnie did!

Stay well,
Carl



TREASURER'S REPORT AS OF JUNE 30, 2013

BY CYNTHIA RUHL, SECRETARY-TREASURER

The finances of the IWMF are accounted for through two separate funds. The Research Fund is used solely to provide funding for research grants that our Research Committee reviews and recommends. Our Member Services Fund provides for all of our outstanding member services, including the Educational Forum, website (*iwmf.com*), and the *Torch*. Both funds are critically important to the work of the IWMF.

The following is a summary of the financial results for the first six months of 2013. The amounts are rounded to the nearest thousand and are unaudited. However, I wanted to share with you where the IWMF stands financially through the first half of 2013.

	Research	Member Services	Total
Revenue	\$ 144,000	\$ 357,000	\$ 501,000
Expenditures	\$ 325,000	\$ 361,000	\$ 686,000
Net Revenue	\$-181,000	\$ -4,000	\$-185,000

Due to generous giving to the Matching Campaign early this year, we are in a very positive position for mid-year. We hope you will continue to support the IWMF throughout the rest of the year as the Research Committee currently has more research projects that have been submitted to us than we can fund. We do have cash reserves to meet our current commitments to our researchers. Our cash reserves at the end of June, 2013 for Research are \$527,400 and for Member Services, \$257,920.

We are also in the final stages of completing the financial audit for 2012. When the audit report and tax return are reviewed and available, they will be posted to the website. As Treasurer, I can assure you that the Board does its very best to make sure every dollar given is wisely spent on serving you, our members, and keeping important research moving forward.

If you have any questions, please feel free to contact me at: csruhl@hrmcps.com

WHAT'S NEW ON THE IWMF WEBSITE?

- A list of hematologists hailing from all parts of the globe with interest and expertise in WM is now available at: iwmf.com/about-wm/finding-a-doctor.aspx
All physicians in this directory have agreed to be included for consultation by other physicians and/or patients. The IWMF does not in any way endorse the individuals listed, nor does the IWMF verify their medical qualifications. The list also includes peripheral nerve specialists who have expertise in treating peripheral neuropathy caused by WM or treatment for WM.
- The list of WM clinical trials has been expanded to include countries other than the US.
See: iwmf.com/treatment/clinical-trials.aspx
- Charts are now available that provide explanations for items that are common to most people's blood tests (like CBC, CMP, HgB, WBC, IgM, MPV, etc.).
See: iwmf.com/about-wm/bloodtests.aspx
- IWMF publications are now available either via mail or by download directly from the IWMF website at: iwmf.com/publications/
- Upcoming support group meetings are now listed on the IWMF website: iwmf.com/services/support-groups.aspx



2013: OUR FIFTEENTH ANNIVERSARY

BY JUDITH MAY, PRESIDENT EMERITA



Carl Harrington with the Torch announcing his election as president of the IWMF.

This year we celebrate the IWMF's fifteenth anniversary as a certified private non-profit foundation. It is only fitting that we take a moment to review the history of the disease known as Waldenstrom's macroglobulinemia, how our organization was developed, and our accomplishments over fifteen years.

The Early Years

It is important to remember, and for new patients to understand, that Waldenstrom's macroglobulinemia is a newly described disease. Dr.

Jan Waldenström, a Swedish hematologist, recognized that he had discovered a separate and distinct blood lymphoma in 1944 and identified elevated IgM as a distinct sign of Waldenstrom's macroglobulinemia (WM). However, for 50 years there was no organization that focused exclusively on WM to assist WM patients.

The seed for the IWMF was actually planted in 1994 when Arnold Smokler, a retired pharmacist in the Washington DC area, was diagnosed with WM. Finding little information available about this disease and no way to locate other patients, Arnie accepted the challenge and went into action.

The first goal was to find other WM patients. Arnie contacted the National Organization for Rare Diseases (NORD) and asked that the names of patients with WM in the Washington DC area be sent to him from NORD's large database of members. NORD sent a list of 21 patients with WM. Arnie next contacted those on the list and invited them to come to the first WM support group. Over the following year, the group increased as more patients learned of its existence. Beginning in 1995 a monthly newsletter was launched. The early issues consisted largely of letters from patients reporting on their treatments. Arnie soon began to access professional journals, publications, and studies and expanded the scope of the newsletter by publishing creditable information on WM. That same year, 1995, he established a website and he named the organization the Waldenstrom's Macroglobulinemia Support Group (WMSG). Other newly diagnosed patients quickly found the website and the beginnings of a national support group took root.

In 1996, Arnie organized the first WMSG conference in Arlington, Virginia, and 75 patients and caregivers attended. Later that year the IRS recognized the WMSG as a not-for-profit organization under the IRS code in section 501(c)(3). In 1997 the second WMSG conference was held with 200 attending. The membership had grown significantly, boasting

10 support groups in the United States and one in the United Kingdom, marking the evolution of the WMSG into an international organization. By early 1998 the organization became known as the International Waldenstrom's Macroglobulinemia Foundation. In the spring of 1998 the first IWMF Educational Forum was held in Atlanta, Georgia, with over 200 attendees. The first Board of Trustees was elected at this Forum. Among the Trustees were Ben Rude and Judith May, who were to become presidents of the IWMF in the future.

The first meeting of the Board of Trustees was also held in 1998. The Trustees set about developing an efficient infrastructure and committee structure. An application for incorporation was submitted to the state of Florida where Arnie then resided, and a small one-person office was established in Sarasota. Sara McKinnie, who continues today as the Office Manager, was our first employee, hired by Arnie.

A Mission Statement was developed in 1999 whose objectives for the new Foundation are basically the same today:

- to provide encouragement and support to WM patients and their families;
- to provide a means of communication for patients and their families;
- to provide information and educational programs that address topics important to WM patients;
- to increase awareness of the issues related to WM;
- to encourage and support research leading to more effective treatment and, ultimately, a cure for WM.

Passing the Torch from Arnie to Ben

In 1999, Arnie Smokler decided that it was time to entrust the Foundation to other strong hands and step down. He left an energized Board of Trustees, the beginning of strong educational programs, and a base for growing contributions. We are forever grateful for Arnie's leadership and dedication to the Foundation and to WM patients.

When Arnie stepped down, Vice President Ben Rude became the IWMF's second President. Ben Rude's contribution to maintaining and strengthening the Foundation was exactly what was needed. During Ben's years as President, membership grew continuously and member services expanded significantly.

Our first IWMF booklets for patients were developed, the number of support groups grew, and the IWMF telephone Lifeline was established. A 17-member Scientific Advisory Committee was put in place. Our SAC is a group of the most prominent physicians and researchers in the WM medical community with Dr. Robert Kyle of the Mayo Clinic as Chair. SAC members review research proposals for appropriate goals, staffing, and budget, and rank the projects for recommendation to fund. This procedure is essential to our Research Program.

2013: Our Fifteenth Anniversary, cont. on page 7



Ben strove to achieve broader awareness and understanding of WM and of the IWmf among the physicians, government agencies, and other cancer organizations in the global arena of cancer research. A natural spokesman for the IWmf, Ben frequented many cancer conferences where he handed out his card and made many beneficial contacts. Judith May was then Vice President for Research and worked for the U.S. Department of Health & Human Services in Washington DC, where many of the meetings and conferences occurred. She frequently accompanied Ben Rude to assist him in building relationships for the IWmf.

One such significant meeting was the first International Workshop on Waldenstrom's Macroglobulinemia, a conference for WM researchers, which occurred in September 1999. In large part the success of this conference was due to the contributions of Dr. Bruce Cheson at the National Cancer Institute (NCI) and of the Office of Rare Diseases at the National Institutes of Health (NIH). The NIH and IWmf jointly funded this first workshop, held in Bethesda, Maryland, with 19 WM researchers in attendance. The International Workshops on Waldenstrom's Macroglobulinemia continue today as a biennial event, most recently in August of 2012 in Newport, Rhode Island. At the Newport Workshop 200 researchers participated, a significant increase in WM researchers compared to the 1999 event. Dr. Steven Treon of the Bing Center for Waldenstrom's Macroglobulinemia at the Dana-Farber Cancer Institute has assumed the responsibility over the years for continuing the Workshops, and we are extremely grateful for his efforts to encourage and expand research in WM.

We lost Ben Rude in January of 2005 from a rare and aggressive T-cell lymphoma that had developed only months earlier. His legacy as President is a permanent part of our history, and Ben will always be remembered.

Judith May Takes the Reins

Judith May was subsequently elected the third IWmf President in February 2005. As a charter member of the first Board of Trustees and Vice President for Research for six years, she was well prepared to assume the role of President.

During Judith's nearly eight years as President, the IWmf experienced continued growth. Improvements occurred in member services and in the IWmf Research Program led by Vice President for Research Tom Myers. Significant changes occurred in the IWmf fundraising program, in the international program, in the support groups, and in volunteer efforts, including a new and far more informative IWmf website and the development of a patient database. Judith's focus was to design a more professional infrastructure of committees, policies, and procedures to guide the Board of Trustees and the Foundation for the future while promoting progress toward the Foundation's goals. All this could not have been accomplished without the huge volunteer effort required to enhance existing services and to develop new services for members. And it could not have been accomplished without the formation of partnerships with other organizations and federal agencies to develop new pathways for the Foundation.

The number of volunteers who came forward to undertake the special projects, committee work, enhanced services, and to become support group leaders made possible the expansion of services and other special projects. The IWmf is strong today due to the efforts of over 100 dedicated volunteers. The Board is an evolving entity, and new Trustees are most often selected from the volunteers and support group leaders who have shown their commitment to help with Foundation work and who have become known to the Trustees. The IWmf Board of Trustees is comprised entirely of volunteer members. Likewise the members of the Research Committee, the support group leaders, the Lifeline counselors, and the *Torch* team are all volunteers.

It is certainly true that the IWmf is an organization of patients helping patients.

Our major partnership with the Lymphoma Research Foundation (LRF) allows the IWmf to join LRF's regional workshops and their annual educational forum and hold separate seminars for WM patients at no cost to the IWmf. Our partnership with the Leukemia & Lymphoma Society (LLS) has greatly improved our research focus. At present we are funding significant research studies on WM jointly with the LLS. The LLS is also now a very important partner in the development of support groups and programs for support group meetings. Our partnering with the European Waldenström's Macroglobulinemia Network (EWMnetwork) enables us to further our international program for WM patients and holds great promise of future partnering on important issues. Having a liaison at the Food and Drug Administration (FDA) has been very beneficial in our understanding of their Orphan Drug Program, the importance of clinical trials, and the role of pharmaceutical firms. Continued contacts with the Office of Rare Diseases at the NIH and with the National Cancer Institute have led to an increased awareness of our small organization on the part of these large agencies. Advice from federal agencies has impacted our research priorities and strengthened our understanding of the large arena of medical research and where the IWmf fits in.

Judith passes the Gavel to Carl Harrington

Today we are beginning a new era with Carl Harrington, the fourth IWmf President, who leads an excellent and highly skilled Board of Trustees. The groundwork is in place for a new phase of development to begin for the IWmf. It is an exciting time for the Foundation and for its members. The changes that will come are necessary and inevitable as the Board works toward a less costly and a more user-friendly electronic system of distributing information. Perhaps services will be redesigned a little differently since more patients are diagnosed at a younger age. Take a moment and think about how you might be able to help. Your help is important to all WM patients today and to all the WM patients who will be diagnosed in the future.

One thing learned from the first fifteen years – in spite of being one of the smallest rare disease organizations, we have earned the reputation of the little organization that could, and did.



THE IWMF RESEARCH PROGRAM

BY TOM MYERS, VICE PRESIDENT FOR RESEARCH,
AND JOHN PAASCH, IWMF RESEARCH COMMITTEE

When the IWMF was established fifteen years ago, a robust research program was envisioned from the first meeting of the Board of Trustees. In 1998 very little was known about the rare lymphoma named Waldenstrom's macroglobulinemia (WM), including its pathogenesis, the existence of familial subtypes, which drugs and treatment regimens were most effective, and why they were effective. Almost every aspect of WM was open to preliminary investigation.

In response to the Foundation's commitment to research, the office of Vice President for Research was established, held first by Judith May and from 2005 to the present by Tom Myers. The IWMF Scientific Advisory Committee (SAC) was also put in place, comprised of outstanding clinicians and researchers with specialized knowledge of WM and created to evaluate proposals for research projects forwarded to them by the Vice President for Research. As planned, projects approved by the SAC are then reviewed and administered by the Research Committee, a group of knowledgeable IWMF members.

In 1999 the first approved research projects were funded by grants from the IWMF Research Fund. Support for research into WM has been provided continuously since 1999, and, with the growth in the number of Foundation members, contributions designated for research have also increased. Since the first grant in 1999, the IWMF has invested over \$6,300,000 into over 35 strategic research projects focused on WM, including those to 18 different individuals representing research organizations in Canada, China, France, Greece, and the US. The recipients reflect the international aspect of the IWMF. Currently the SAC and the Research Committee are evaluating four new grant proposals. More requests are expected in the future.

As we look back on fifteen years of progress in understanding and managing WM, it is quite impressive to document the impact that the research program of this small foundation has made.

Generally speaking, the funded projects fall into three broad categories, and the following list of researchers and their projects funded by IWMF grants reflects these same categories:

- Exploratory research into the pathogenesis of WM and the discovery of promising new ways to target WM cells
- Translational research to discover if drugs used for other cancers are effective against WM cells or if new targets identified in exploratory research result in improved therapies

- Research to develop appropriate WM "tools" for use in testing new drugs

EXPLORATORY RESEARCH INTO THE PATHOGENESIS OF WM AND THE DISCOVERY OF PROMISING NEW WAYS TO TARGET WM CELLS:

Pathogenesis refers to the origin and development of a disease. Understanding this process can identify promising new targets for the treatment of WM.

2000 Vincent Rajkumar, M.D., Mayo Clinic.

Dr. Rajkumar looked at blood vessel growth in WM patients and showed that this was not a factor in the characteristics of WM, although important in multiple myeloma to predict severity of the disease.

2001 Rafael Fonseca, M.D., Mayo Clinic.

In this study Dr. Fonseca aimed to identify and confirm translocations and deletions in parts of certain chromosomes. Comparing his results to other forms of hematological diseases, he found that in WM there frequently is a deletion in a region of the 6q chromosome.

2004-2005 Constantine S. Mitsiades, M.D., Dana-Farber Cancer Institute.

Dr. Mitsiades performed studies of proteins that regulate the growth and death of WM cells. His studies resulted in the development of new treatments such as Velcade.

2004, 2006, 2011 Stephen M. Ansell, M.D., Ph.D., Mayo Clinic.

A series of grants awarded to Dr. Ansell supported his investigation of the role of BLyS (B-cell Lymphocyte Stimulator) as well as proteins such as STAT3 and STAT5 that are within the WM B-cell. Dr. Ansell's projects have greatly increased the understanding of the microenvironment surrounding the WM cancer cells and the roles of various proteins in the process of secreting IgM. His current grant will run into late 2014.

2004 Linda M. Pilarski, M.D., Ph.D., Cross Cancer Institute in Alberta, Edmonton, Canada.

Work performed by Dr. Pilarski revealed several genetic characteristics of WM, including the finding that many mutations in the gene for HAS1 are present in WM B-cells but not in a patient's healthy cells. Presence of these mutations, which lead to alternate splicing of the HAS1 gene, may identify those WM patients with higher risk of disease progression.

2007 Esteban Braggio, Ph.D., Mayo Clinic.

Dr. Braggio performed an analysis of B-cells from 42 WM patients to identify mutations as well as genomic alterations

The IWMF Research Program, cont. on page 9



that could affect the NF- κ B pathway in WM B-cells. His research showed that these differences could lead to a more active role for the pathway of NF- κ B, which in turn is a key promoter of many genes that lead to inflammation, innate immunity, cell growth, and apoptosis (cell death).

2007 Anastasia S. Tsingotjidou, D.V.M., Ph.D., Aristotle University, Thessaloniki, Greece.

The success that Dr. Tsingotjidou had in developing a xenograft WM mouse model led to a further study funded by the IWMF to investigate the presence of peripheral neuropathy associated with WM. The study showed that peripheral neuropathy could be detected in mice that had WM, and this finding may allow scientists to study peripheral neuropathy in animals.

2007 Steven P. Treon, M.D., M.A., Ph.D., Dana-Farber Cancer Institute.

In this comprehensive study into the genetic basis and pathogenesis of WM, Dr. Treon identified three subtypes of the disease among WM patients which he designated the sporadic WM subtype, the familial WM only subtype, and the familial mixed B-cell disorders subtype. The three have distinct genetic and epigenetic differences. Further analyses performed by Dr. Treon and his research team may lead to understanding why WM B-cells do not differentiate into plasma cells, why certain patients have a more aggressive disease, and may suggest novel targets for the treatment of WM.

2010 Steven P. Treon, M.D., M.A., Ph.D., Dana-Farber Cancer Institute.

In 2010 Dr. Treon was awarded a grant to conduct a study based on whole genome sequencing (WGS) performed on both WM cells and healthy cells of WM patients. His group then analyzed the results of the WGS. The result created much excitement when it was announced in 2011 because it led to the discovery of a mutation in the gene that produces the protein MYD88. The mutation is identified as L265P and is found in WM B-cells of 90% of the patients tested but not in their healthy cells. This very high percentage of a single point mutation is a very rare occurrence and has attracted much interest in the greater WM clinical and research communities. Several other studies around the world have also demonstrated that a high percentage of WM patients have the MYD88 mutation. Better understanding of the significant role of this mutation is important, and the IWMF has initiated funding to address this issue, see below page 10.

2010 Travis J. Henry, Ph.D., and Rafael Fonseca, M.D., Mayo Clinic.

Dr. Henry and Dr. Fonseca investigated the relationship of the typically elevated level of IL-6 in the serum of WM patients with the amount of hepcidin, an important hormone in the regulation of proper iron levels. Hepcidin inhibits iron transport in the gut, thereby preventing excess iron absorption; it also inhibits transport of iron out of the macrophages where it is stored. Increased IL-6 levels lead to the production of

too much hepcidin, which in turn reduces the amount of iron absorbed from the gut and traps it inside the macrophages. When iron becomes unavailable, the result is a reduced level of hemoglobin in red blood cells and thus anemia.

2012 Abdel Kareem Azab, Ph.D., formerly at Dana-Farber, currently at Washington University.

Dr. Azab presented the hypothesis that hypoxia (low oxygen levels) within cells is a contributing factor leading to the dissemination of WM cells within the bone marrow. He is currently in the second year of a two-year research effort, and he is making good progress. Dr. Azab plans to see if targeting the proteins involved in hypoxic conditions can reduce the spread of WM cells within the bone marrow.

TRANSLATIONAL RESEARCH: Translational research describes efforts directed toward converting basic research discoveries into new clinical and research tools, medications, and therapies. This area of research supported by the IWMF studies the effect on WM of drugs and different forms of treatment that have proven efficacious in other forms of lymphoma or that have evolved from insights gained into the pathogenesis of WM.

2000 Ayad Al-Katib, M.D., Wayne State University.

A study of the effects of certain agents on the growth of WM cells was conducted earlier by Dr. Al-Katib. For this study the first cell line of WM was developed. He then treated the cell line and mice in which the cell line had been injected, first with 2CdA, a known WM treatment agent, and then 2CdA combined with the chemical bryostatin, derived from a marine animal. The combination of agents appeared to be more effective than either one alone. Today, scientists find that in general combinations are more effective than a single-agent treatment. Unfortunately, this cell line proved to be unstable over time.

2000 Steven P. Treon, M.D., M.A., Ph.D. Dana-Farber Cancer Institute.

The monoclonal antibody Rituxan (rituximab) was a recent addition in 2000 to the short list of drugs effective against WM. Dr. Treon studied how Rituxan works in WM patients to understand the resistance to Rituxan experienced by some patients and to develop new potential therapies. One result was to identify Campath 1-H as an FDA-approved monoclonal antibody effective against WM cells.

2004 Christopher Bredeson, M.D., M.Sc., F.R.C.P.C.A., and Hari Parameswaren, M.D., International Bone Marrow Transplant Registry, Medical College of Wisconsin.

Stem cell transplants (SCT) are a possible, though infrequent, form of treatment in WM. In 2004 the IWMF funded Dr. Bredeson and Dr. Parameswaren to do a retrospective study of WM patients who had received a SCT. The study showed that while both allogeneic SCT (receiving stem cells from a donor) and autologous SCT (receiving your own stem



cells) were effective, there is higher mortality risk in having an allogeneic STC. Also, if there is the possibility of an autologous STC in the patient's future, he or she should avoid receiving nucleoside analogues and certain alkylators, as they may affect the mobilization of stem cells.

2006 Irene M. Ghobrial, M.D., Dana-Farber Cancer Institute.

Dr. Ghobrial investigated the drug perifosine in mice with WM and in cell lines in "test tubes" and demonstrated that perifosine inhibits the growth of WM cells. Her previous work indicated that perifosine interrupts a development pathway causing WM cells to seek shelter in the bone marrow. Perifosine also appears to cause WM cells that are already sheltered in the bone marrow to be released into the peripheral blood where they can be destroyed by other reagents. This project enabled Dr. Ghobrial to test the blood of patients before and after they were treated with perifosine to determine if the same effects occur in humans. The results showed that perifosine as a single drug prolonged the time to progression in patients with relapsed or refractory WM. The response rate was 36%. It was also shown that perifosine in combination with Rituxan and Velcade increased WM cell death.

2010 Brad Nelson, Ph.D., Tev and Joyce Deeley Research Centre, Victoria, BC, Canada.

Dr. Nelson aims to use therapeutic vaccination to enhance the anti-tumor T-cell response in patients with WM and other lymphoid cancers. This research was wholly funded by the WMFC, the Waldenstrom's Macroglobulinemia Foundation of Canada. The discovery of the mutated MYD88 gene presents a possible target for enhanced T-cell response, and the possibility of vaccination against WM has gained further interest.

2011 Xavier Leleu, M.D., Hôpital Huriez, Lille, France.

Dr. Leleu proposed to test pomalidomide, a derivative of thalidomide, for beneficial effect in WM. Part of his research involved WM cell lines, including one developed under an effort co-funded by the IWMF. He demonstrated that pomalidomide was not efficacious in WM and through detailed research determined that the low level expression of a particular protein, cereblon (CRBN), in WM was a primary cause of the drug's inactivity.

2013 Steven P. Treon, M.D., M.A., Ph.D., Dana-Farber Cancer Institute.

This grant is for a follow-on effort that will investigate the role of the MYD88 mutation in WM B-cells that was discovered in an earlier effort co-funded by the IWMF. Dr. Treon is looking into the development of new drugs, or the use of presently available drugs, to target the elements of the MYD88/NF- κ B pathway that appear to be constitutively activated in WM B-cells. One protein that is being considered as a target is IRAK1/4.

THE DEVELOPMENT OF "TOOLS" FOR THE STUDY OF WM:

The study of a disease requires the proper "tools," and the IWMF realized this early in its research program and provided for "tool" development almost from the start. The drive to develop "tools" was accelerated in 2008 when the Leukemia & Lymphoma Society (LLS) sponsored a workshop in Washington DC where scientists from around the world met to develop a program that would lead to understanding WM. The recommendations from this workshop were to develop cell lines representative of the disease, breed mice that would acquire WM because of their genetic predisposition (transgenic mice), and provide a tissue bank of WM cells available for all scientists. These "tools" would allow research of the disease and its treatments without using human patients. Following these recommendations, the IWMF is supporting the development of cell lines, tissue banks, and animal models.

CELL LINES:

2010-2012 Stephen M. Ansell, M.D., Ph.D., Mayo Clinic.

2010-2014 Asher A. Chanan-Khan, M.D., formerly of Roswell Park Cancer Institute, now at Mayo Clinic.

2010-2011 Suning Chen, Ph.D., Soochow Hospital, China.

2010-2013 Irene M. Ghobrial M.D., Dana-Farber Cancer Institute.

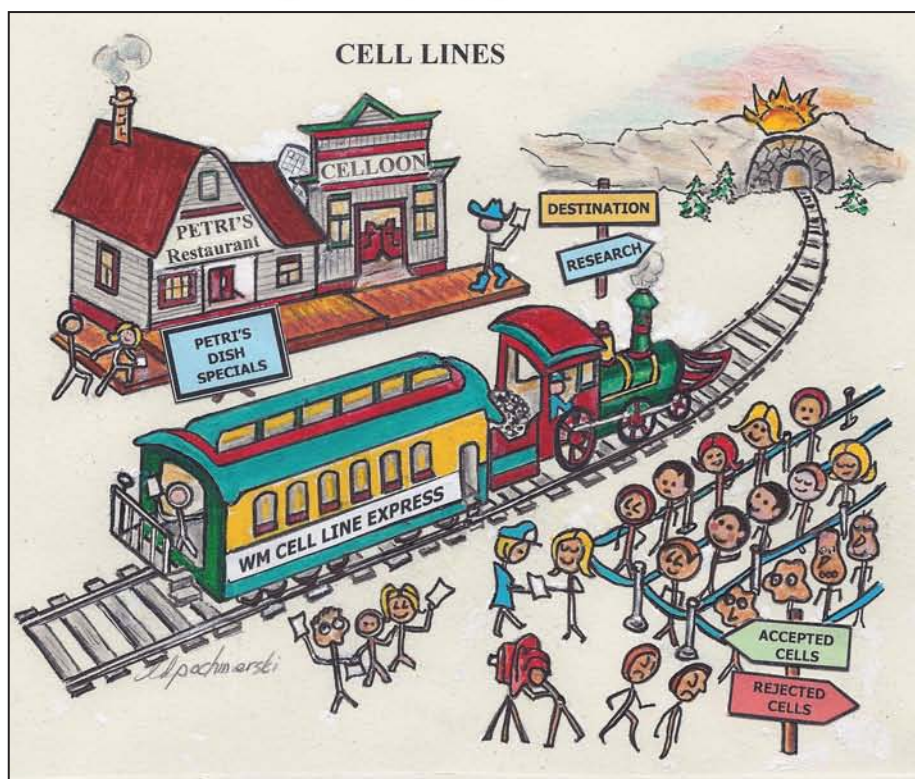
The IWMF and the LLS are partners in supporting research aimed at developing cell lines representative of WM. Cell lines are cultures of cells grown under controlled conditions in a laboratory. A cell line is derived from one particular cell type and can reproduce indefinitely and without changing, which makes it very useful for research purposes. Four researchers at different locations started in 2010 to develop cell lines. Dr. Ansell of Mayo was successful in developing a stable representative cell line. Dr. Chanan-Khan of Roswell Park also developed a cell line that has proved useful in WM research. Dr. Chen of China and Dr. Ghobrial of Dana-Farber have encountered difficulties in producing acceptable cell lines.

TISSUE BANK:

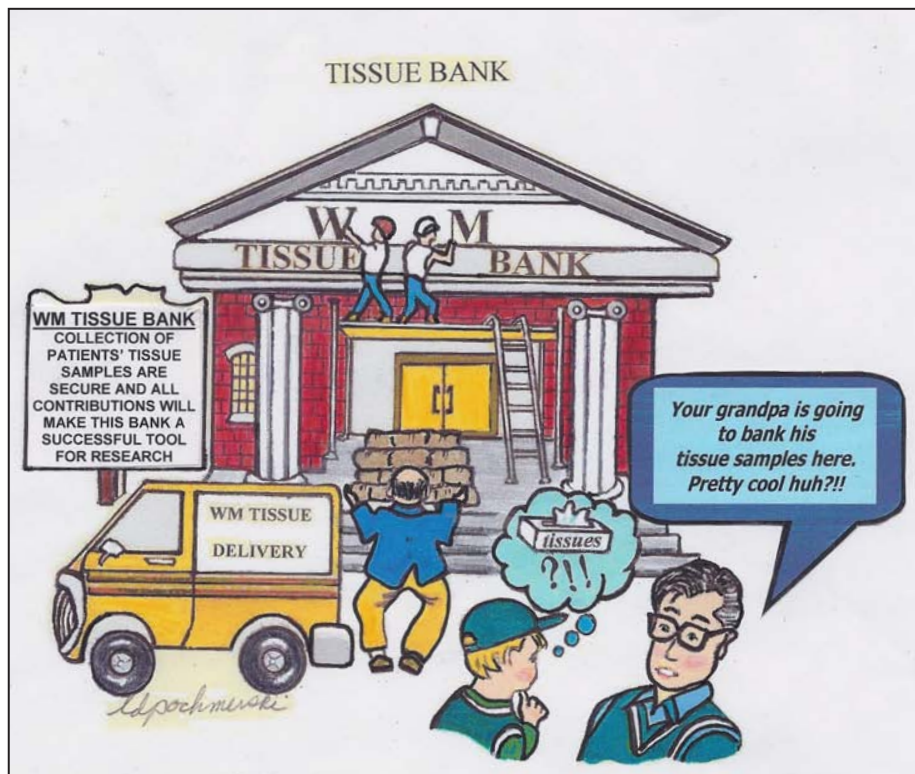
2010-2016 Irene M. Ghobrial, M.D., Dana-Farber Cancer Institute.

In 2010 Dr. Ghobrial submitted a grant request that includes establishment of a tissue bank to contain 1,000 samples of bone marrow material from WM patients. In addition, the project seeks to obtain epidemiological surveys from the patients providing the tissue samples. Progress has been extremely slow because of the difficulty in obtaining fresh bone marrow biopsy material. By 2013 only 90 fresh bone marrow, 325 peripheral blood, and 90 saliva samples have been collected. Dr. Ghobrial has a large number of previously collected samples embedded in paraffin, and she is working





Validated as stable, suitable, and successful, cell line candidates representative of WM wait in line with the anticipation of making the journey forward for WM research endeavors.



Tissue banks have made important contributions to research on many major diseases and a tissue bank is now being created as a research tool for WM.

to determine if those samples can be used in the same manner as the fresh bone marrow samples.

MOUSE MODELS:

2007 Anastasia S. Tsingotjidou, D.V.M., Ph.D., Aristotle University, Thessaloniki, Greece.

The first mouse model sponsored by the IWMF was developed by Dr. Anastasia Tsingotjidou, who implanted both adult human WM bone marrow samples and healthy bone marrow samples into a mouse, each into a separate hind limb. All these xenograft mice had increased levels of IgM after only one month, but these levels decreased by the second month before rising again. The cause for this rise in the first month may be similar to the flare often seen by people when they receive Rituxan. Additionally, she was able to demonstrate that WM cells were not only able to survive in the mouse but were able to metastasize to the healthy transplanted bone marrow sample.

2010 Siegfried Janz, M.D., Ds.C., University of Iowa.

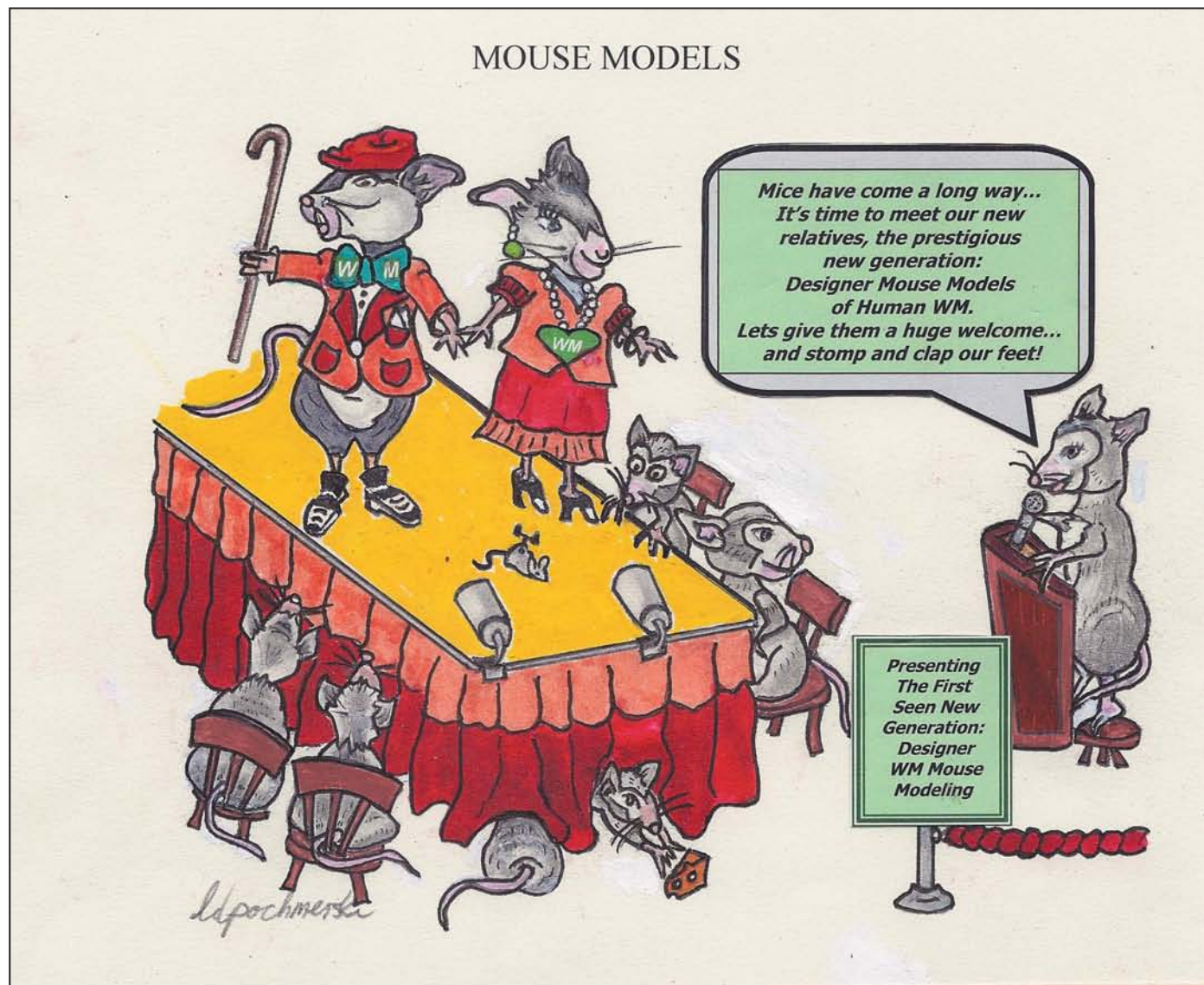
The second mouse model grant funded by the IWMF was awarded to Dr. Siegfried Janz who has successfully altered mice genetically (transgenic mice) so that they have characteristics representing the biology of WM and can pass these characteristics to their offspring. These changes include the overproduction of IL-6 and BCL-2, two proteins prevalent in WM. Dr. Janz created a new mouse model by using two different mouse lines with overexpression of these proteins plus a mouse with disabled production of AID (activation-induced cytidine deaminase), which is key in the switching of the production of antibodies by B-cells from the IgM type to other types such as IgG or IgA. The new mice containing all three genetic characteristics were able to produce tumors and excessive IgM. Unlike the mouse model developed by Dr. Tsingotjidou, the genetically

altered mouse line of Dr. Janz can be reproduced from sperm stored at the Jackson Laboratory in Maine.

2012 Ruben Carrasco, M.D., Ph.D., Dana-Farber Cancer Institute.

The most recent WM mouse model, funded by the Leukemia & Lymphoma Society and the Waldenstrom's Macroglobulinemia Foundation of Canada and scientifically supported by the IWMF SAC and the Research Committee, is under development by Dr. Reuben Carrasco at Dana-Farber. This conditional transgenic mouse will have the mutation

in the gene for MYD88 that was discovered by Dr. Treon's group in the WGS effort co-sponsored by the IWMF. As described elsewhere, this mutation was present in 90% of the patients sequenced and is a significant finding. The total impact of this mutation is yet to be determined, but having a mouse line with this conditional mutation will provide a tool to understand its role in the pathogenesis of WM and be a key platform to evaluate drugs affecting the pathways influenced by MYD88.



Designer Mouse Models, who are engineered to model disease characteristics of WM, are presented making their runway debut.

CONCLUSION:

The list of grants funded by the IWMF between 2000 and 2013 not only reveals the Foundation's strong commitment to research since its establishment but also demonstrates significant progress in expanding knowledge about our rare disease. This progress is true also of research being conducted

worldwide into WM. Advances based on genomic research now offer the possibility of drugs that treat WM as a chronic condition and may even offer the possibility of a cure. It is an exciting time for WM research, and the IWMF will be an active participant.



IMAGINE A CURE

BY MICHAEL SESNOWITZ, VICE PRESIDENT FOR FUNDRAISING

The new *Imagine a Cure* Campaign was announced at the IWMF 2013 Educational Forum in San Diego in late May. The goal is to generate \$9,000,000 in commitments over a 5 year period to fund both research and member services. Commitments can be pledges paid out over a 2-5 year period or one-time gifts. Donations may be made with cash, financial assets such as stocks, bonds, and mutual funds, real assets such as land, or legacy gifts. The aim is to raise \$4,500,000 for research, \$2,700,000 for member services, and \$1,800,000 in legacy provisions that can be directed to either research or member services. I hope you will choose to participate.

When I was diagnosed with WM two years ago, I left my doctor's office remembering three words: rare, cancer, and incurable. I assumed I had little time left and began to get my affairs in order, wanting to minimize the disruption to the lives of those I would leave behind. In my quest to gain a better understanding of WM, I discovered a truly remarkable organization, the IWMF. By reading IWMF booklets on immunology and treatment options, I began to learn about the disease and, perhaps more importantly, I began to gain hope. By joining IWMF-TALK, I was able to learn from the experiences of others. When I posted a question about a treatment option, I received responses from WMers on three different continents. When I wanted to talk to someone who had experienced that same treatment, I turned to the IWMF Lifeline. A wonderful woman, who knew only that I was a newly diagnosed patient, spent over an hour on the phone helping me understand the pros and cons of the treatment from a patient's perspective. I will never forget her kindness.

My wife and I were no longer dealing with this disease alone; we had quickly become part of a very caring and supportive community, a feeling that was further enhanced when we joined our local support group. That sense of community made an enormous difference in my life.

Then, in 2012, I attended the Ed Forum in Philadelphia and saw first-hand how IWMF-funded research was transforming the treatment of WM. World class scientists and clinicians reported on their work, and it was clear that many of the advances I learned about resulted from research that had been supported by the IWMF. I was amazed at how accessible the researchers were and was thrilled to be able to discuss their work with them. Here was an organization that not only met the immediate needs of patients and their families through the extensive provision of member services, but also addressed their long term welfare by supporting research that could lead to better treatments, and possibly a cure.

After attending the Ed Forum, I moved the IWMF to the very top of my charitable giving priorities.

Every fall I teach a course in public finance to college juniors and seniors. One topic we spend some time on is the difference between public and private goods. Private goods are rival in consumption, which simply means that you and I cannot consume the same slice of bread. Public goods, on the other hand, are non-rival in consumption. Once a public good is provided, one person's consumption does not preclude another's. Scientific research is an example of a public good. Once the results of the research are disseminated, one person's use of those results does not preclude another's. For many public goods exclusion from consumption is either very difficult or impossible, so the benefits are both non rival and widespread. These are the reasons that the Federal Government supports research through agencies such as NIH and NSF. The government steps in because the private sector will under-allocate resources to the provision of public goods such as research.

But while the federal government spends billions of dollars on medical research, it provides virtually no support for research on WM because WM is an orphan disease. This is why it is imperative that the IWMF raise funds for research and that **all of us** support the *Imagine a Cure* Campaign. The government ignores us because there are so few of us, and because there are so few of us, we cannot rely on other WMers to provide the funding. If we don't all participate, the research won't be done.

Unlike the government, the IWMF does not have the power to tax. We rely on the enlightened generosity of our members and their families and friends. Given our small numbers, each and every pledge matters. And because many research projects are multi-year undertakings, **multi-year** pledges are essential if these projects are to be undertaken.

I believe the IWMF is the best steward of my research dollars because its Scientific Advisory Committee (SAC), comprised of the most talented WM researchers from around the world and under the very able leadership of Dr. Robert Kyle, guides the allocation of funds to the projects with the greatest potential payoffs. Every dollar designated for research goes to support an SAC approved project. Not one penny is used for overhead.

Since 1999, the IWMF has provided more than \$6,300,000 in WM research funding. In 2008 leading WM researchers from around the world were asked to identify the knowledge gaps that were limiting progress on WM research. They identified the following:

- An inadequate understanding of the importance of familial genetics in WM
- The lack of a WM mouse model

Imagine a Cure, cont. on page 14



- The absence of reliable WM cell lines
- The absence of a WM tissue bank
- The lack of genomic sequencing in WM patients

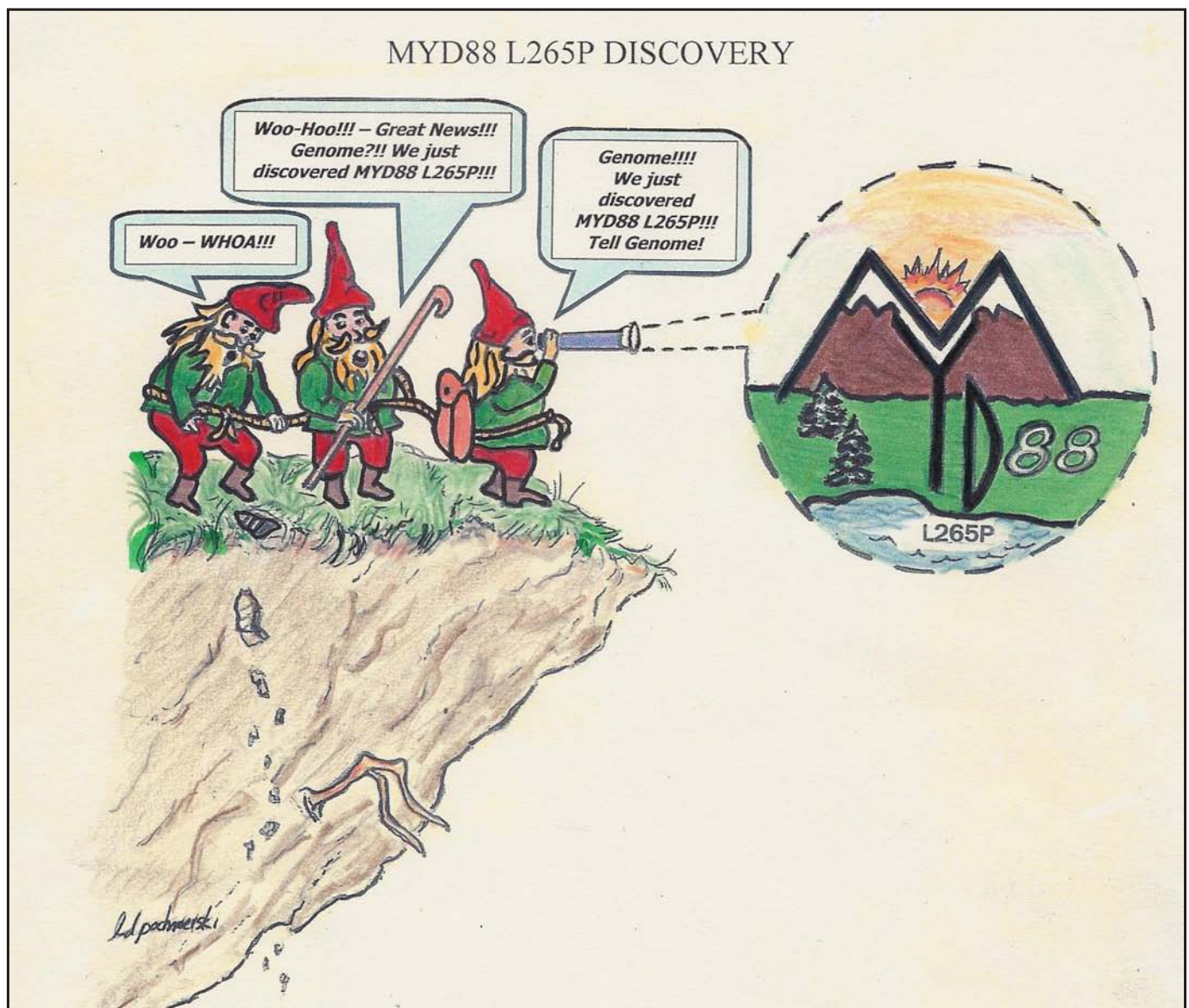
With the aid of our SAC, IWWMF research funding has addressed each of these issues.

A Dana-Farber study found that more than one-fourth of patients with WM had a first or second degree relative with a B-cell lymphoproliferative disorder. Knowing whether or not a specific patient's disease is family-based is important because there is some evidence that the efficacy of treatments may vary with whether or not the disease is familial.

There are now reliable cell lines that were developed by Dr. Stephen Ansell and by Dr. Asher Chanan-Khan, both of the Mayo Clinic, that are being used by researchers throughout the world to test the effectiveness of new drugs and new treatments against a common standard – a standard that stays constant from test to test, from country to country, and over time.

A mouse model has been developed by Dr. Siegfried Janz of the University of Iowa, and further work in this area is continuing.

A WM tissue bank is being developed by Dr. Irene Ghobrial of the Dana-Farber Cancer Institute. This will help researchers understand WM cells in various stages of the progression of the disease.



Like the Genome Gnomes who have arrived on a new plateau, the discovery of MYD88 L265P mutation, made possible by Whole Genome Sequencing, brought WM research to a new level of understanding the signaling pathways that allow WM cells to grow and survive. A new horizon lies ahead for further discoveries.



Whole genomic sequencing performed by Dr. Steven Treon and his research team at the Bing Center for Waldenstrom's Macroglobulinemia at the Dana-Farber Cancer Institute has led to the exciting discovery of the MYD88 mutation that is shared by 90 percent of WM patients. Among other things, the mutation activates Bruton's tyrosine kinase, permitting the survival and proliferation of WM cells. The BTK inhibitor ibrutinib, which received Breakthrough Therapy Designation by the FDA for Waldenstrom macroglobulinemia earlier this year, may very well become the first drug that wins FDA approval for WM.

While the clinical trial results for ibrutinib are very encouraging, it is not a cure. The MYD88 mutation activates other pathways, and these may need to be shut down before WM can be fully controlled or cured. Work along these lines is continuing at the Bing Center at Dana-Farber and it is essential that we be able to continue to fund this type of research.

The successes that have resulted from IWmf research funding have suggested new paths for the research to take and have led to an increase in the number of researchers who want to study WM. That's very good news for all of us. But this good news presents us with the challenge of finding the increased dollars needed to fund these new projects. It's up to us to ensure that proposals approved by our SAC do not go unfunded so that the talented researchers who want to study WM can continue to work on our behalf, to find better treatments, and, yes, to find a cure. With momentum on our side, let's not allow these researchers to turn their attention to other diseases. Let's keep them fully employed, working on finding a cure for WM.

While much of my own giving will support research, a portion of it will go to member services. I will never forget the critical role the IWmf played in my life when I was newly diagnosed, and I want the organization to be there for those who will be diagnosed in the future.

The array of member services provided is, of course, not just for the newly diagnosed. I don't think a day goes by when

I don't make use of at least one of these services. IWmf-Talk continues to provide me with important information on a daily basis. The articles posted by Peter DeNardis are always interesting and informative. I learn from both the questions asked by participants and the responses posted. The series of WM booklets provides valuable information about immunology, treatments, and medical tests, answering so many of the questions that I have. These booklets will always need to be updated as new discoveries are made. The articles in the *Torch* are always enlightening, bringing me up to date on new research developments, examination and treatment protocols, happenings at the support groups, and so much more. The patient database allows us to plot our lab results, making it easier to spot trends. The Ed Forums give us all a chance not only to hear about the latest research developments, but to talk to the researchers and clinicians who are leading the way to better treatments and a cure. Where else could one gain access to so many leading experts on so rare a disease?

I hope you will join my wife and me in making a **multi-year** pledge to the *Imagine a Cure* Campaign. You may choose to designate your gift to research, to member services, or to a combination of the two. You can give cash, stocks, bonds, mutual funds, real property, or a legacy gift. For a five year commitment of \$50,000 or more (\$10,000 per year) you can establish a named gift fund. For \$250,000 or more you can establish an endowment. You can make your pledge or gift by using the enclosed envelope or going to our website (iwmf.com) and clicking on the new campaign using the link on our home page.

If you are over 70 and a half, you can donate up to \$100,000 of your required IRA distribution this year. Under certain circumstances doing so could reduce your taxable income by more than the magnitude of your gift.

The momentum is there. Let's not let it die. It's up to each and every one of us to ensure the success of the *Imagine a Cure* Campaign by making as generous a contribution as we possibly can. Only together can we defeat WM.

FIFTH INTERNATIONAL PATIENT FORUM ON THE HORIZON

It's not too early to begin making plans to attend the Fifth International Patient Forum, to be held in London on August 18, 2014, at the Park Plaza Westminster Hotel. The IWmf, WMUK, and the Bing Center of the Dana-Farber Cancer Institute are working together to make this an outstanding patient event. The program will include guest speakers, an Ask the Doctor session, and a comprehensive roundup of the latest research on WM led by Dr. Steven Treon of the DFCI in the afternoon.

Attendance is limited to 220. Bookings for the Fifth International Patient Forum will be available on the WMUK website wmuk.org.uk later in this year.



FIFTH ANNIVERSARY OF THE BEN RUDE HERITAGE SOCIETY

BY LAURIE RUDE-BETTS

At this year's Educational Forum in San Diego, eleven new members were inducted into the Ben Rude Heritage Society. The year 2013 is the fifth anniversary of the Society, established in 2008 in honor of my late husband, the second President of the IWMF. Through this Society, Ben's leadership and legacy live on, and I am honored to have served as chairperson for these past five years.

The eleven members inducted in 2013 made provisions for the IWMF either through bequests, gift annuities, trusts, insurance policies, or similar planned gifts. With these gifts, the IWMF will ensure support for those affected by WM and fund continued research in WM on behalf of the 1,500 patients who are newly diagnosed every year, as well as for veteran patients.

In 2008 eleven founding members were enrolled, and the Society was started with gifts totaling over one quarter of a million dollars. In only five short years the total has reached \$1,852,141!

Lynn Martin is this year's first inductee. Diagnosed in 2008, Lynn is the vice-president and co-owner of New Wave Technologies. Among his favorite activities, he lists golfing, investing, and spending time with his family. Last year Lynn attended the IWMF Educational Forum held in Philadelphia. At the awards luncheon where the new members of the Ben Rude Heritage Society were recognized, Lynn was inspired to put the IWMF in his estate plans. We are very thankful that Lynn was motivated to do so!

At San Diego the following Society members were honored posthumously: C. Edwin Baker, Arlou Brahm, Robert and Anne Coulbourn, Leslie C. Guthrie, Jr., Evelyn Klein, Janet Levy, Brandt Norquist, and Allan Shaw. One inductee asked to remain anonymous.

As a token of the Foundation's appreciation, inductees or their survivors are presented with a crystal sculpture that is personalized appropriately with their name and the date of presentation. La Vey Norquist, the wife of Brandt Norquist, made this comment when she received the Ben Rude Heritage Society award on behalf of her husband: "The lovely award is

a daily reminder of Bud's fervent hope that soon, very soon, this dreaded disease will be only a bad memory from the past." And Les Guthrie's wife, Mary Ann, wrote to say, "The Ben Rude Heritage Society award is sitting on my desk next to a beautiful orchid that a friend gave me when Les died. I hope that, through your continued fundraising efforts, new and better treatments will be made available to patients with Waldenstrom's."

We thank these donors and their families for their generous gifts and for showing their support for the Ben Rude Heritage Society!

As you reflect on this year's roster of inductees to the Ben Rude Heritage Society, you should know that this group reflects a cross section of our membership and that it has grown by one third in the past year. Society members have made legacy provisions in order to ensure the long-term viability of the IWMF. Their generosity ensures that we will be able to continue to provide services for patients well into the future and that we will be able to fund research leading to better treatments and possibly to a cure.

Legacy provisions are an important part of the IWMF's future, and the legacy portion represents 20% of the *Imagine a Cure* Campaign. If any of you are thinking about your personal estate planning, I hope you will consider including the IWMF as a beneficiary. If you would like more information about ways to leave a legacy gift, please contact the IWMF office or Dave Benson, the IWMF's Senior Development Officer. We will be happy to tell you more about how you can be a part of the Ben Rude Heritage Society and the exciting *Imagine a Cure* Campaign.

Please remember how important you are to the IWMF as we are such a small family of rare cancer patients. Without your support we would not be able to provide the necessary educational resources to our members and our research needs would go unmet. Your planned gift to the *Imagine a Cure* Campaign ensures that your legacy and leadership, too, will live on through the Ben Rude Heritage Society of the IWMF.

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



RONALD G. DRAFTZ: JUDITH MAY VOLUNTEER OF THE YEAR AWARD

BY JUDITH MAY, PRESIDENT EMERITA

Volunteer: to choose to act in recognition of a need with an attitude of social responsibility and without concern for monetary profit, going beyond one's basic obligations.

The history of volunteerism in America is long and rich and is the lifeblood of many organizations.

A nonprofit organization cannot succeed without a strong corps of volunteers. It is due to the large number of volunteers within the membership of the IWMF that our Foundation can provide so much to so many. Recently the Board of Trustees determined that a special IWMF award was in order to recognize each year an outstanding volunteer and decided to call it the Judith May Volunteer of the Year Award. I thank the IWMF Board of Trustees for this great honor, as volunteerism is something I strongly believe in and have participated in for most of my life. It is at the heart of the IWMF.

It is fitting and proper that the first Judith May Volunteer of the Year Award should go to Ronald Draftz, a man who embodied all the virtues of the word *volunteer*.

Ron was a humble man with a great compassion for others. The foremost memory for many newly diagnosed patients, and especially patients with serious medical issues, was the day they received a call from Ron Draftz. Whether Ron was speaking by phone, or face-to-face, or even by e-mail, it was immediately obvious that this was a person of keen intellect with an amazing knowledge of Waldenstrom's macroglobulinemia. His caring nature and willingness to talk at length regarding any concern one had is well remembered by the great many patients he helped through difficult times, providing comfort, support, and advice.

Among the many roles and projects Ron took on as a volunteer, the most significant are:

- Co-Support Group Leader of the large Chicago patient group;
- Dedicated member of the Research Committee;
- Scientific Advisor on the *Torch* team, spearheading the Doctor On Call articles;
- Back-up moderator for IWMF-Talk and valued contributor;

- Rescuer of a Patient Database Project who expanded and revised it to the point of being ready for patient registration after it had fallen by the wayside ten years earlier;
- Official photographer for the IWMF Educational Forums for many years;
- Initiator of the quirky 10K CLUB, an exclusive club for WM patients whose IgM had reached a level of 10,000 or more.

Ron will always be remembered by many for his compassionate counseling and his deep knowledge of our disease and the science behind it. The hours – even years – he devoted to helping WM patients were given wholeheartedly so that others would be aided in their time of need.

Ron passed away in August of 2011. We miss him very much. It is a true honor to name Ronald G. Draftz as the first recipient of the Judith May Volunteer of the Year Award.

Ron's daughter Angelique Draftz received the posthumous award at the IWMF Patient Educational Forum in San Diego, California, on May 17, 2013, representing Ron's family including her mother, Germaine, and her siblings David and Aimée.

THANK YOU

To all IWMF Members –

You have been so generous in your e-mails and notes of thanks to me personally, and in the donations in my honor that have come to the IWMF office, and I thank you for this. The time I've spent working to help build the IWMF is reward alone, but it has meant a great deal to me to read your heartfelt notes, the comments in the 'two-foot' thank you card! and in the album of photos and notes given to me at the IWMF Ed Forum in May. I am very grateful that I had the opportunity in life to be the President of this wonderful organization.

I continue to stay involved as the first President Emerita of the IWMF, working to establish a Patient Advocacy Program, and as a member of the Research Committee. I'm also available to assist President Carl Harrington and the IWMF Board of Trustees as they continue the Foundation's momentum.

I look forward to seeing you at the next Educational Forum in Tampa, Florida.

With warmest regards and best wishes for your health,

Judith May



REMEMBERING ARNIE SMOKLER AND THE EARLY DAYS OF THE IWMF

AS RECALLED BY DAVELL HAYS AND LAURIE RUDE-BETTS

On the occasion of the Fifteenth Anniversary of the IWMF, Davell Hays and Laurie Rude-Betts share with the Torch their personal recollections of IWMF Founder Arnold Smokler and his tireless efforts, not only to bring WM patients in contact with one another but also to establish an organization that would share and spread knowledge of this almost unheard of type of non-Hodgkin's lymphoma.

Laurie begins: What can I say about Arnie, except that we owe it all to him? As a pharmacist, a man of science, he wanted to know all about the disease with which he had been diagnosed, but there was little information published. Thankfully, this was the time when the Internet was gathering steam, and Arnie was able to put the name of the cancer out there and begin to communicate with others, especially those who were afflicted. Ben Rude was fortunate in that his diagnosis in 1996 came after colleagues at the college where he taught acquired a PC. They not only found Waldenström's macroglobulinemia on the Internet, they also came upon the reference to the support group and Arnie's phone number. I will never forget how relieved Ben was after an hour-long conversation with Arnie. It meant the world to us for Ben to be able to talk to someone who had knowledge and experience and who actually **had** WM and who was in contact with others afflicted with this mystery cancer!

The first time we were face-to-face with Arnie was when he had, I believe, the second support group meeting in the Washington DC area, and Arnie's dear wife, Bernie, and his son and daughter were all helping run the meeting. Arnie had lots of plans to expand the scope of the support group, and Ben was determined to help him. In 1998 the first Educational Forum was held in Atlanta and the first Board of Trustees was elected. Later in the same year, at the first meeting of the Board of Trustees, Ben was elected Vice President. Until this time, Arnie did it all!

Davell recalls her first contact with Arnie Smokler. As his support group increased in size, participants realized the need for a formal organization.

When I was first diagnosed in 1993, there were only about 20 known cases of WM. (My best friend discovered this through the National Organization for Rare Diseases.) Arnie Smokler contacted each individually and started a chat line. As a pharmacist, Arnie was able to provide input to the chat line from his medical knowledge. He would always go out of his way to help people. After my friend found Arnie's site, and I joined in, Arnie often talked to me personally, through e-mail and by phone. We quickly developed a friendship and mutual respect. My own proclivity was for alternative and complementary methods. Arnie supported me in my

contributions to the site, encouraging me and all respondents to study, research, try new things, and then always to share our growing information. Arnie was tireless in his contributions. It became the center point for his life.

People felt totally free to say whatever they wanted on the chat line – it was a place of great comfort in a world where there were very few doctors who even knew what WM was. Can you imagine what a thrill it was to find another person who had your same disease when you had come to believe you were fighting this thing almost alone?

As the number of participants grew, we realized that there might really be a significant number of us. So far there was no organization paying attention to our disease, no research being performed to help us. We soon understood that if there was to be any hope of extending our lives, and hopefully finding a cure, a formal structure would be needed to stand up for us and to apply pressure to both government and private organizations. Our chat line was attracting more and more people, and some of them had significant skills in a number of professional areas. Those who were more vocal started exploring a possible future for us.

A group of ten or so of us agreed to meet and discuss ideas. Things started falling into place as we each found our own specialties. What an amazing group of people. We were all willing to give so freely of our time and resources. I had strong organizational skills and became Arnie's right hand man (okay, woman) as Secretary. As we divided up duties to make best use of our talents and time, it always centered on Arnie as the leader. We realized that we would need to fund our own research since our small patient base would not be enough to spur research in WM. In order to accomplish this, we needed a formal, tax-exempt organization. We formed the Board, we wrote up mission statements and articles of incorporation. We learned how to raise funds. We learned how to evaluate research proposals. We all worked tirelessly.

To bring people and ideas together, Arnie suggested holding an educational forum and inviting those doctors with whom we had developed relationships. Arnie did most of the work to put the first few Ed Forums together. Soon we realized that we needed to be polished and professional to inspire people to donate and to help raise funds. A huge part of our success is due to the fabulous doctors and researchers we were able to attract. Everyone was operating as volunteers, but as time went on and funds became available, we were able to pay for the travel required for the Board meetings. Another essential thing for our success was to be able to have a central physical

Remembering Arnie Smokler, cont. on page 41



END STAGE WM: FACE TO FACE WITH MORTALITY

BY EUGENE TURNER, IWWMF MEMBER



Eugene Turner

Hello Fellow WMer's,

Before I was diagnosed with Waldenstrom's macroglobulinemia I had never heard the word nor had anyone near or far from me. I didn't necessarily ask "why me?" as much as I wondered from whence came the cause of this cancer.

I am a male Afro-American from a medium-size town in central New York State. I went through high school

doing pretty much what everyone else did. I suffered the usual childhood diseases such as chicken pox, measles, and mumps. The area had an industrial-based economy and supported a large military air base. During the summers I worked in a copper mill as a generic machinist and laborer. I cannot say that in looking back I was exposed to any out-of-the-ordinary substance. I spent a few years at a mid-western university before I finally settled in central California in 1970.

Like many in the 60s, I experimented with recreational drugs and then went on to become a vegetarian for about 15 years. I was always physically active in sports and outdoor activities. I am 6 feet 2 inches tall with an average weight of 190 pounds. I worked in construction building houses in my younger years, then got involved with computers and photography. Life was normal and uneventful.

About five years prior to my diagnosis, I began to notice subtle changes in my health and stamina. I did a lot of high-country backpacking back then and noticed a slight decrease in my ability to do as I used to. I also began to get minor nosebleeds, maybe one every three to four months. They would last for only a couple of minutes. My primary care doctor attributed both symptoms to aging. A few years later, in January of 1996, my annual checkup revealed an elevated urine protein level. My doctor was not very concerned and made a note to check it again the next year. But just to be sure, he also referred me to Dr. John Fisher of Sutter General Hospital. My appointment was for September 19.

The night of August 19, 1996, my world changed. I woke up, tried to get out of bed, and nearly passed out. I had a relentless case of vertigo. I crawled around the house for several days. When I finally was able to make it to my general practitioner, he began treating me for flu. To be fair, it was flu season.

After a week or so with no response to the flu medication, I began to notice a slight blurring of my vision while reading the

newspaper. At first I thought it was my imagination. Finally, my vision became so blurred that I went to an optometrist who could find nothing wrong except bleeding on my retinas and "sausaging." I was given eye drops. Next my hearing gradually began to fade. I went to an audiologist and was given eardrops. During the same period, my weight dropped from 190 to 165 pounds. Then I had what were described later as two "near heart attacks." While lying on the couch, suddenly my heart "skipped" a beat. I heard an audible non-rhythmic pounding in my chest for a few scary seconds.

In September, a day or so before my scheduled appointment with my oncologist, Dr. Fisher, I woke up from a nap and realized I had lost 70% of my vision and the ringing in my ears was so loud I could not understand people talking to me. On the evening of September 17, 1996, I was admitted to Sutter General Hospital's intensive care unit. I was 48 years old and in critical condition.

That first night in the ICU was very emotional. When the flurry of activity subsided and the room cleared, I found myself alone. We often speak of WM from the technical side – the science, the drugs, the treatment protocols. Seldom do we talk about the emotional impact. As I lay there in that hospital bed, I assessed my situation. I knew I was really sick. I was acutely aware of the fragility of my existence. I was in pain. I was nearly blind and deaf. I had difficulty breathing. I had a weird, ominous feeling, a dark cloud, hanging over me. Suddenly, I thought: I'm dying. Like now. The terror struck me like a lightning bolt. I burst into tears and began to tremble. Dreadful images flooded my mind. I asked myself: How will I know? Finally, exhausted, I drifted unknowingly into sleep. I awoke the next morning to a needle prick, thankful to see the morning. Day one? I wondered. Maybe?

That day I was given four units of blood along with a unit of platelets. I called the lab phlebotomists "vampires" because for the first couple of weeks they drew blood every four hours, day and night. Have I mentioned I hate needles? The evening of the second day, Dr. Fisher entered my room and said those dreaded words, "You have cancer." I will never forget the impact those words had on me. The first diagnosis was bone marrow cancer, lymphatic cancer, and leukemia. Gee, I felt special. My blood test results were WBCs: 10.2, RBCs: 2.7, Hgb: 5.8, Plts: 87, an IgM of 14,000 mg/dL (a normal level is less than 300 mg/dL), and a serum viscosity of 16 (because it was so high, the doctors requested a Serum Protein Interpretative Analysis Report). Dr. Fisher explained to me that the heart, vision, and auditory problems were because of the high serum viscosity. A bone marrow biopsy was done to get a more specific diagnosis. When the lab sent back the results, I was diagnosed with WM. At this point, I

End Stage WM, cont. on page 41



WHEN TO MOVE FROM WATCH AND WAIT TO TREATMENT

BY MORIE A. GERTZ, M.D., M.A.C.P.

Dr. Gertz is the Roland Seidler, Jr., Professor of the Art of Medicine and Chair, Department of Medicine, Mayo Clinic Minnesota. E-mail: gertz.morie@mayo.edu

Due to the advanced technologies available for the detection of abnormal proteins, an increasing number of Waldenström patients are found to have monoclonal IgM proteins in their blood and Waldenström cells in the bone marrow but to have no symptoms. When screening is done for patients over the age of 50, approximately 1 person in 200 in the United States will have an IgM protein and, therefore, is at risk for the development of Waldenström macroglobulinemia. Virtually all patients with Waldenström macroglobulinemia have a detectable IgM protein that precedes the diagnosis. In fact, the risk of the development of Waldenström macroglobulinemia in the presence of an IgM protein is nearly 8000 times that of the general population.

Since Waldenström macroglobulinemia is a very slowly progressive process and is currently incurable, there is no advantage to initiating therapy in the absence of symptoms. If the disease were curable, it would be proper to administer the cure and never worry about it again. Unfortunately, this type of early intervention has not been shown to prolong survival. If quality of life could be demonstrated to be better in patients on treatment, this would be a justification for the treatment of asymptomatic individuals. Unfortunately, all of the treatments available for Waldenström macroglobulinemia have potential side effects and late risks. Therefore, treatment is not considered to be associated with an improved quality of life in an otherwise asymptomatic patient. That raises the question, “When is it proper to have treatment?” A similar question concerns those patients who have already received treatment and are back on observation and being monitored: “When is the re-initiation of therapy appropriate and when is it inappropriate?”

It cannot be overemphasized that the level of the IgM protein should not be used as a criterion for the initiation of therapy. In other words, there is something wrong in saying “We’ll begin treatment when your IgM is 2000 or 3000 or 8000, etc.” if the patient is otherwise asymptomatic and there are no other associated risks. That being the case, what are the common symptoms that need to be monitored in patients who are on “watch and wait?”

The answers are not straightforward and require close collaboration with your medical oncologist. Different patients will have a different set of symptoms based on the specifics of their disease, and symptoms manifest differently, so that there is no one right answer that would be applicable to all patients. Although it is not the only criterion for initiating therapy, the most common reason why patients require treatment is a progressive decline in their red blood

count. This results in increasing levels of anemia whose symptomatic manifestation is progressive fatigue, shortness of breath with exercise, difficulty climbing stairs, etc. Typically, as Waldenström evolves, the IgM level will climb over time, and a rise in protein generally means that there is an increase in the number of abnormal Waldenström cells in the bone marrow. As these cells increase in number, they will begin to interfere with the bone marrow’s normal function of blood production, leading to a progressive decline in the red blood cell count and resultant anemia. If a patient has a rising IgM level and the blood count is falling and continues to decline – usually at a slow rate but the patient is beginning to develop fatigue, apathy, or shortness of breath – therapy is justified since it will destroy the Waldenström cells in the bone marrow. Destruction of the Waldenström cells allows for improved production of red blood cells and correction of the anemia. Anemia is the most common indication for the initiation of treatment.

In some patients, the platelets that are produced in the bone marrow are also affected. Platelets are the cells that clot the blood. When production of the platelets is impaired, although this is an uncommon development, treatment is justified even if symptoms are absent. If the platelet count falls too far, patients are at risk of bruising or bleeding. Moreover, the treatment of Waldenström with some of the available highly effective agents can further lower the platelet count. And if the platelet count is allowed to drift down excessively before therapy is initiated, it could increase the risk of treatment-related bruising or bleeding. Although there is not a specific cutoff, in my practice I would initiate therapy if the platelet count had fallen to one-half the normal level.

Occasionally patients require treatment because of elevation of the serum viscosity level. One cannot estimate the serum viscosity clinically. It must be measured to confirm hyperviscosity syndrome. The most reliable signs of hyperviscosity syndrome are the presence of nose-bleeding and gum bleeding that are difficult to control. Patients with nosebleed caused by hyperviscosity typically have to undergo multiple episodes of cautery before the problem is recognized. Hyperviscosity can cause risk to vision and can cause serious eye bleeding and, when elevated to extreme levels, can be a trigger for the initiation of therapy.

Occasionally patients will need treatment because of weight loss or night sweats or rapid progression in the enlargement of lymph glands. These are uncommon developments and should raise suspicion in the oncologist’s mind that the Waldenström may have converted to a more aggressive form of lymphoma. Nonetheless, there is a small proportion of patients in whom these so-called “constitutional symptoms”

When to Move, cont. on page 43



Ed Forum Album 2013

Created by Alice Riginos and Sara McKinnie

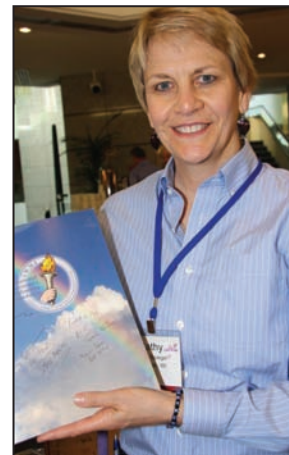
Ed Forum 2013, the eighteenth annual Educational Forum devoted to the disease Waldenström's macroglobulinemia, was held in San Diego, California, on May 17-19 at the Westin San Diego. The summaries of the scientific papers presented at Ed Forum 2013 have already been published in the *Ed Forum Review 2013* and are available at iwmf.com. This album of photographs represents the highlights of the Forum for those who could not attend and is a souvenir for those who were present in San Diego.

Of all the Member Services provided by the IWMF, the Ed Forum requires the greatest effort to organize and

to direct during three intense days of formal lectures, breakout sessions, and social events. Attendees hear about the very latest research conducted on WM from the leading researchers themselves. And, equally important, attendees also profit from this unique opportunity of meeting informally with others who are facing the challenges of living with WM. The confidence inspired by casual meetings and conversations outside of the lecture hall is tremendous – and really only possible at an IWMF Ed Forum.

We owe many thanks to our photographer, Jack Whelan, for the photos reproduced in this album.

Friday morning, May 17



Eager participants are arriving from all directions. Sanjeev and Sucheta flew in from Dubai! At 9:00 sharp the Ballroom Foyer is ready for registration.



A selection of IWMF publications and other printed materials was available in the registration area throughout the Forum. The newest update to our *Treatment Options* booklet was snapped up quickly.



Your hard-working Ed Forum Committee members were on hand to keep things flowing smoothly. From left to right: Sara McKinnie, Elena Malunis, Guy Sherwood, Carl Harrington, Sue Herms.





Ed Forum 2013 opened officially at 10:00 am when President Carl Harrington welcomed those attending the Friday morning session. The group then split into two different tracks during the morning – one for the Newly Diagnosed and one for Veteran patients.

For the afternoon's plenary session – and for those on the following two days – the ballroom was transformed into a lecture hall with double projection and seating in rows at desks for note taking.

The audience's intense interest in the proceedings is evident!

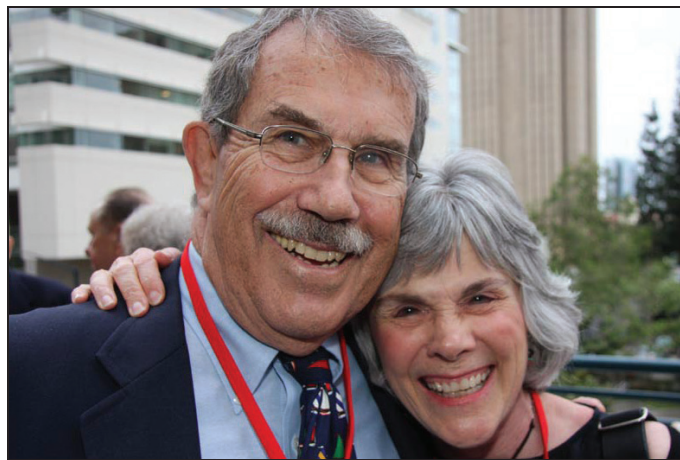


The afternoon's program included breakout sessions directed to smaller groups who were seeking more specific information, for example information about a particular treatment, from patients who have first-hand experience. In the afternoon sessions, led by experienced 'veterans,' Rituxan, Velcade, Bendamustine, Plasmapheresis, and Stem Cell Transplants and Stem Cell Banking were the topics covered.

The reception and dinner on Friday evening provided an occasion for attendees to mix and mingle, making new acquaintances and friends.







At the conclusion of dinner, the Board of Trustees surprised President Emerita Judith May by taking this opportunity for the Foundation to express its gratitude for her service and leadership over the fifteen years she sat on the IWMF Board of Trustees, for eight of those years in the office of President.

An enormous card signed by Ed Forum attendees was given to Judith by current President Carl Harrington. Office Manager Sara McKinnie prepared a charming scrapbook filled with photographs and letters sent to Judith when she stepped down from the presidency earlier this year. And on behalf of the Board, Tom Myers presented Judith with a set of stunning hand-blown glass wine goblets. Judith was visibly surprised and delighted by these wonderful gifts.



Judith next stepped up to the podium to inaugurate a new award for the IWMF, the Judith May Volunteer of the Year Award. This award, which honors Judith herself as an example of boundless volunteerism, is to be given annually in recognition of exceptional service rendered to the Foundation by one individual. Judith



announced that the late Ronald Draftz was the first IWMF volunteer to be so honored for the extraordinary impact he had on the Foundation (please see the article on page 17 of this issue). A lovely engraved crystal sculpture was presented by Judith to Ron's daughter, Angelique Draftz, who was present to represent the Draftz family.

The evening closed with a keynote speech by Jack Whelan who recounted his personal experiences as a WM patient, experiences that alternated between the amusing and the sobering.



Saturday, May 18



Zachary Hunter, Dr. Robert Kyle, and Dr. Steven Treon



Dr. Joseph Mikhael



Dr. Irene Ghobrial and Dr. Robert Kyle



Dr. Stephen Ansell and Dr. Ranjana Advani





Dr. Stephen Ansell

Saturday was a full day of presentations by leading researchers and clinicians discussing the very latest results of research in WM, ranging from an explanation of cell cytokines, an update on the WM tissue bank, integrative oncology, the significance of the MYD88 L265P mutation, and new information on WM treatments including ibrutinib. The speakers also made themselves available to Forum attendees throughout the day. Attendees looking for specific information found the opportunity to pose their questions in an informal way with leading authorities on WM. More breakout sessions were held in the afternoon on the topics of Caregivers, Pain Management, the Patient Database, the Newly Diagnosed, and Familial WM.

For their service on the Board of Trustees, well-earned 'World of Thanks' awards were presented to Judith May and to Cindy Furst. Earlier this year Cindy left the Board after serving as Trustee for four years.

A highlight of the award luncheon was the induction of eleven new members for 2013 into the Ben Rude Heritage Society. Lynn Martin was present to receive his award and was warmly thanked by Laurie Rude-Betts, Chair of the Society. All inductees had made provision in their estate plans for gifts to the IWFM. Please see page 16 of this issue of the *Torch* for further details concerning the inductees and the Ben Rude Heritage Society.



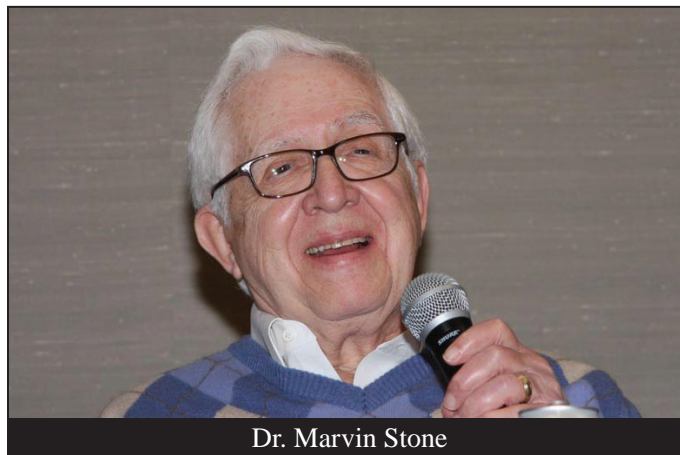
As is now the tradition, Ed Forum 2013 closed on Sunday morning following the ever-popular Ask the Doctor session moderated by Dr. Robert Kyle. Over the previous two days, Forum attendees were encouraged to submit questions they would like to hear discussed by a panel of experts. This was the opportunity to hear a second – or possibly a third – opinion in answer to the questions selected from the submissions by Dr. Kyle.

Panelists for 2013 were: Dr. Mary Lou McMaster, Dr. Marvin Stone, Dr. Steven Treon, Dr. David Maloney, and Dr. Morie Gertz.

Sunday, May 19



Dr. Mary Lou McMaster



Dr. Marvin Stone



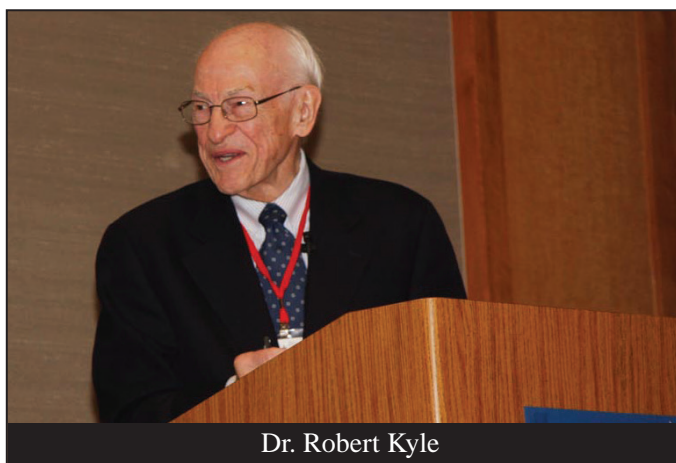
Dr. Steven Treon



Dr. David Maloney



Dr. Morie Gertz



Dr. Robert Kyle

Congratulations are due to the members of the Ed Forum Committee who planned the program of speakers for the Forum, made the arrangements at the Westin, and supervised the proceedings so effortlessly. Thanks, too, to Office Manager Sara McKinnie and all the office staff for all the hard work that set the Foundation on course for a successful Forum.

It was a terrific Ed Forum in every way! See you next year in Tampa!



MEDICAL NEWS ROUNDUP

BY SUE HERMS

Phase II Trial of Ibrutinib in Relapsed/Refractory WM Reported – Dr. Steven Treon at Dana-Farber Cancer Institute presented preliminary data of a Phase II trial of the oral BTK inhibitor ibrutinib in 35 relapsed/refractory WM patients at the International Conference on Malignant Lymphoma in Lugano, Switzerland. The best overall response rate was approximately 83% (11.4% very good partial responses, 54.3% partial responses, 17.1% minor responses). The safety profile observed in WM patients was similar to that in other B-cell malignancies. Grade 3 and higher adverse events were infrequent, with thrombocytopenia (decreased platelets) and neutropenia (decreased neutrophils) seen in 8.6%. The study has been expanded by an additional 28 patients to further evaluate the safety and efficacy of ibrutinib.

Study Analyzes the Prevalence of Autoimmune Disorders in WM Patients – A joint study by the University of Connecticut, the Hospital of the University of Pennsylvania, and St. Francis Hospital in Hartford, CT, performed an analysis of the prevalence of autoimmune phenomena in WM patients and compared it with the general population. This small study found that 58.3% of WM patients had autoimmune disorders, including pernicious anemia, Hashimoto's thyroiditis, immune thrombocytopenia, autoimmune hemolytic anemia, chronic inflammatory demyelinating polyneuropathy, pure red cell aplasia, polymyalgia rheumatica, temporal arteritis, and ANA positivity. Most of these conditions significantly exceeded overall prevalence in the general population, although the authors note that analysis of larger cohorts is needed to confirm these observations.

Data Presented on Phase II Trial of Panobinostat in Relapsed/Refractory WM – A multi-center U.S. Phase II trial reported data on single-agent panobinostat in patients with relapsed/refractory WM. Panobinostat is an oral histone deacetylase inhibitor. A total of 36 patients received either 25 or 30 mg three times a week. Minimal response or better was achieved in 47% of patients. In addition, 50% of patients achieved stable disease, and none showed progression while on therapy. The median time to first response was 1.8 months, and median progression-free survival was 6.6 months. Grade 3 and 4 toxicities included thrombocytopenia (decreased platelets), neutropenia (decreased neutrophils), anemia, leukopenia (decreased white blood cells), and fatigue.

Data on ABT-199 for Relapsed/Refractory NHL Presented at ASCO – An international Phase I study of the oral BCL-2 inhibitor ABT-199 for relapsed/refractory non-Hodgkin's lymphoma was recently reported at the 2013 ASCO Annual Meeting. A single dose (50-400 mg) was administered followed by 6 days off drug prior to the initiation of continuous once daily dosing. As of January, 31 patients were enrolled. The most common adverse events

were nausea, diarrhea, dyspepsia (indigestion), vomiting, fatigue, pyrexia (fever), and cough. With a median follow up of five months, 29 patients were evaluable for efficacy. The overall response was 55%, and the three WM patients in the trial achieved a partial response.

Disappointing Results Reported for Monoclonal Antibody Belimumab in WM – A joint Phase II study conducted by the Peter MacCallum Cancer Center in Australia and the Nottingham City Hospital in the U.K. reported disappointing results on the use of belimumab as a single-agent monoclonal antibody therapy for WM. Belimumab targets the BLYS (B-lymphocyte stimulator) protein that is over-expressed in B-cell malignancies, including WM. Twelve patients were enrolled in the study; although 10 patients had stable disease with therapy, no objective responses were seen.

Japanese Study Discusses Incidence of WM in Japan and Taiwan – A Japanese study from the Teikyo University in Tokyo and the Nagasaki University Graduate School of Biomedical Sciences discussed the incidence of lymphoplasmacytic lymphoma (LPL)/WM in both Japan and Taiwan, based on cancer registries from 1996-2003. A total of 280 new cases of LPL/WM were recorded in Japan and 56 in Taiwan, with the median age at diagnosis being 73 and 67 years, respectively. The incidence showed male predominance in both countries, and age-specific incidence rates increased sharply with age, especially in people over 65 years old. Incidence rates per 100,000 person-years were 0.043 in Japan (0.071 for men and 0.023 for women) and 0.031 in Taiwan (0.041 for men and 0.020 for women). Rates in Japan and Taiwan were lower than rates reported in the literature for Asians living in the U.S. A significant increasing trend was observed in the incidence over the period from 1996-2003 in Japan alone.

LLS and Dana-Farber Cancer Institute Establish Network for Community-Based Trials for Blood Cancer Therapies – The Leukemia & Lymphoma Society (LLS) has joined the Dana-Farber Cancer Institute to establish a network of sites for clinical trial testing of innovative blood cancer therapies in community oncology settings across the U.S. The Blood Cancer Research Partnership will bring clinical trials closer to where patients live and help to address one of the primary bottlenecks in the development of new cancer therapies – the need for more patients to take part in trials. Eleven potential sites have been identified in the following states: New York, Georgia, Colorado, Illinois, California, Florida, Texas, Kansas, Tennessee, New Jersey, and Washington. LLS is investing \$1,050,000 in the three-year project.

New FDA Warning Added for Risk of Thrombosis with Immune Globulin Therapy – The U.S. Food and Drug

The IWMF Research Program, cont. on page 29



Administration will now require manufacturers to add information on thrombosis (blood clotting) risk to the current boxed warning on the labels of all intravenous, subcutaneous, and intramuscular human immune globulin products. The new warning will include factors that can increase the risk of thrombosis and possible ways to reduce risk.

Bendamustine Approved by Health Canada for Relapsed Indolent NHL – In April, bendamustine was approved by Health Canada for treatment of relapsed indolent non-Hodgkin's lymphoma and chronic lymphocytic leukemia. It has been listed on provincial formularies in the western provinces and is expected to be listed on formularies in Ontario and the Atlantic provinces very shortly. Health Canada is the Federal agency tasked with the responsibility for maintaining the health care system and for managing health care costs in Canada.

Enzastaurin Is Discontinued – Eli Lilly and Co. is ending development of enzastaurin after it failed in a Phase II trial to delay disease relapse in patients with diffuse large B-cell lymphoma who had been previously treated with CHOP or R-CHOP therapy. Enzastaurin is an oral small molecule serine/threonine kinase inhibitor and was being compared in the trial to a placebo for patients at risk of relapse.

Obinutuzumab (GA101) Results Reported for Relapsed/Refractory Indolent Lymphoma – Obinutuzumab (GA101) was tested in a Phase I/II Study of relapsed/refractory indolent lymphoma, with results reported in the *Journal of Clinical Oncology* by Hospices Civils de Lyon-Université de Lyon in France. This drug is designed to hit the same molecular target (CD20) that rituximab does. In this trial, 40 patients were randomized to receive two different dosing schedules. The higher dosing schedule showed an overall response rate of 55% vs. 17% for those in the lower dosing schedule, and 9% of the higher-dose group had a complete response, compared with none in the lower-dose group. Among rituximab-refractory patients, 5 of 10 achieved a response in the higher-dose group vs. only 1 of 12 patients in

the lower-dose group. Median progression free survival was 11.9 months in the higher-dose patients and 6 months in the lower-dose patients. The most common adverse events were infusion-related. The higher-dose schedule of 1,600 mg on days 1 and 8 of cycle 1 and 800 mg on day 1 of cycles 2 to 8 is undergoing further development. A simplified schedule using 1,000 mg for all cycles with doses on days 1, 8, and 15 of cycle 1 is now moving to Phase III testing.

Phase II Study Reports Results on Idelalisib (GS-1101) in NHL – Gilead Sciences announced interim results from a Phase II study evaluating idelalisib (formerly GS-1101 or CAL-101), an oral inhibitor of PI3K, for the treatment of patients with indolent non-Hodgkin's lymphoma that is refractory to rituximab and to alkylating-agent chemotherapy. In this study, single-agent treatment with idelalisib achieved an overall response rate of 53.6%, with a median duration of response at this interim analysis of 11.9 months. The most common Grade 3 or 4 adverse event was diarrhea, with elevations in liver function tests and neutropenia (decreased neutrophils) also being reported.

Cold Caps to Be Tested to Prevent Hair Loss during Chemotherapy – Researchers in California and New York will begin testing the effect of cold caps to prevent hair loss in breast cancer patients undergoing chemotherapy. Cold caps have been used in Europe and Canada to prevent or minimize hair loss, but they have not yet been FDA-approved in the U.S. Near-freezing temperatures are supposed to reduce blood flow in the scalp, making it harder for chemotherapy drugs to reach and harm hair follicles. The researchers are using a brand of cold cap called DigniCap. The tight-fitting, insulated cap is attached to a cooling machine during chemotherapy to maintain a temperature of 41 degrees F.

The author gratefully acknowledges the efforts of Peter DeNardis, Wanda Huskins, and John Paasch in disseminating news of interest to the IWMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.

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FROM IWMF-TALK

BY JACOB WEINTRAUB, M.D.

I am honored to have been invited to continue the “FROM IWMF-TALK” column for the *Torch*. For those of you who don’t know me, I am a semi-retired pediatrician and I have had WM for the last twelve years. I have been followed locally in western Michigan and at Mayo Clinic in Rochester, MN. For the entire period I have been on watch and wait. I have been a member of IWMF-TALK for the past eleven years, joining after developing a mild PN.

During the past months, the topics covered on IWMF-TALK have varied from old subjects, such as peripheral neuropathy, IV access versus ports, plasmapheresis, and established treatments, to newer subjects, especially the recently published articles by Dr. Steven Treon about the MYD88 mutation and the newest treatments including ibrutinib. There are always newly diagnosed patients just learning about WM who have many questions, and likewise older patients confronting new developments and experiences and treatments. Recently there were discussions about sudden onset of deafness, concerns about travel, and about the process of drug approval and how it affects us.

IBRUTINIB:

Many people on clinical trials with ibrutinib have reported excellent results with this new treatment. **Mitch O** reported that his IgM has decreased to 700, though in a later post he reported IgM down to the 400 range and hemoglobin increased to 15.7. He feels strong and normal – he had forgotten that he could feel this way. He voiced concern about the need to continue to take ibrutinib and whether this might lead to reduced efficacy in the future. Mitch has had no significant side effects except for some weight gain and two acne flares. **Hank S** is also participating in the ibrutinib trial, and he is tracking his IgG closely. It has always been in the normal range but has decreased somewhat during the trial.

IWMF President **Carl Harrington** reported a conversation with Dr. Treon about whether a person needed to have the MYD88 mutation in order for ibrutinib to work. Dr. Treon reported that at this time there is no reason to avoid ibrutinib treatment even if a person does not have this mutation. **Sue Herms**, Board Trustee, pointed out that CLL (chronic lymphocytic leukemia) and mantle cell lymphoma patients are using ibrutinib with a great deal of success, and the MYD88 mutation is apparently not as prevalent in those diseases as it is in WM and may even be absent.

There was some discussion about the mechanism of action and whether ibrutinib, a BTK (Bruton’s tyrosine kinase) inhibitor, actually kills WM cells. The question was put to Dr. Treon, and he agreed that, in fact, WM cells are killed by this new treatment.

Board Trustee **Pete DeNardis** posted an article about a Phase II study by Dr. Treon. This study showed that the overall response rate was 83%, with very good partial response of 54.3%. Bone marrow disease burden decreased overall from 70% down to 40%. Serious adverse effects were infrequent, with thrombocytopenia and neutropenia seen in 8.3% of patients studied.

Stay tuned as more clinical trials are started and more of us report out experiences with ibrutinib.

BENDAMUSTINE:

Bendamustine also brings much ongoing discussion. Most people are reporting very good results with few side effects. Many are using this in combination with Rituxan. However, there seems to be a group of patients being treated with bendamustine whose lab results do not show much change.

David B was 3 months into his bendamustine with ofatumumab treatment but was not seeing any results, good or bad, except for a reduction in IgM (but IgM level has never been that much of a problem for him). Ofatumumab is also known as Humax CD-20, a humanized monoclonal antibody that functions in the same way as Rituxan. He asked for others to comment on their results with this treatment or with bendamustine and Rituxan.

Carolyn C reported on her bendamustine treatments combined with Rituxan. She had mild nausea, persistent tiredness, and some GI symptoms that were not as bad as anticipated. She did not feel much better until 2 months after the last bendamustine treatment. Her legs and hands now feel much stronger, and she is able to play guitar at a higher level again. This is significant because of her initial presentation with severe neuropathy. She has noticed a steady decrease in her IgG, though it is still in the normal range. Her M-spike is barely measurable.

Kay D is approaching her last of 6 bendamustine infusions. She also has been receiving Rituxan. Kay now has much less fatigue, no anemia, much lower IgM. She responded right away, and by the third month she was feeling “pretty darn good.”

However, **David B** reported that his latest blood work showed dangerously low platelet and white cell counts, so the second round of infusions of bendamustine and ofatumumab have been delayed. He also reported that his IgM has decreased from 2060 to 1720.

One issue with bendamustine is its effect on veins. Many people reported vein hardening or clotting with bendamustine infusions. **Charles S** is in the middle of a 6-cycle treatment with bendamustine and Rituxan. He noticed an irritated

From IWMF-Talk, cont. on page 31



section of the infusion vein, and it was hard to the touch. The infusion nurse added a bag of saline to the infusion tubing to dilute the “benda” as it entered the veins and that has helped. Others have also reported less vein hardening when the bendamustine is more dilute than is usual. **Arno M** reported that his oncologist brackets the bendamustine infusion with 0.5L of saline, one infusion before and one after the bendamustine, which seems to prevent irritation of his infusion vein.

PORTS VERSUS IV ACCESS:

There was considerable discussion about use of ports, PICC lines, and veins for IV access.

Megan D reported that her husband **Mark** had always used his veins only, due to the need for free movement of his arms in his profession as a mural artist. However, when he started treatment with bendamustine, he opted for a port, also usable for plasmapheresis. So far this port has only been used for chemo, and Mark has avoided the hardening others experienced with IV bendamustine.

Liane C reported her port insertion and plasmapheresis were all done as outpatient procedures, with the insertion done under local anesthetic. It was painless. During the plasmapheresis procedure, she was able to eat, move around, and walk. At home, she was even allowed to take showers, and she was also able to do field work out in rural Wisconsin. It made chemotherapy and blood draws easy. Her port has a double lumen, tunneled under her skin, so the ports hang down on her chest, out of the way.

Board Trustee **Guy Sherwood, M.D.**, reported that a single lumen port is useless for plasmapheresis, but useful for chemo infusions, especially bendamustine and other harsh chemos. However, **Scott K** was adamant about trying to avoid ports if at all possible. He voiced concern about the need to keep ports clean and the potential for infection. Scott has managed very well with all infusions and plasmaphereses by just using his arm veins.

A WM RIBBON?

There was even some discussion about the appropriate color for a ribbon specific for WM patients. **David S** found out that non-Hodgkin lymphomas use lime green ribbons as their color.

However, **John P** reported that Christopher Patterson of the Bing Center had pearl colored wristbands with “Waldenstrom’s Macroglobulinemia” etched in them that have been available on a table at one or more of the Ed Forums. A general discussion followed about why people wear a cancer ribbon or bracelet in the first place. **Christopher C** suggested wearing a bracelet is not likely to help find other WM patients, since there are so few of us. However, one reason to wear a bracelet or ribbon is to raise awareness, and others reported that their bracelets have generated discussions about WM and about cancer in general.

This is just a sampling of the discussions on IWMF-TALK. As new members join and treatment recommendations change and long-time members report changes in their status, I expect the discussions will continue to be informative, supportive, and upbeat. Tune in to IWMF-TALK for the latest information!

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
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
2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name



IN THE TORCHLIGHT

BY LINDA POCHMERSKI



Bill and Linda Pochmerski

Linda Pochmerski is the artist who created the cartoons, based on current IWMF research projects, that enliven this anniversary issue. In a personal essay, Linda reflects on how her creativity, nurtured from childhood, is so very important to her life today.

Life is not about finding yourself, it is about creating yourself.
~ George Bernard Shaw

Little did I know when I first read this quote that it would arouse so much curiosity and tag along with me as if it had a significant reminder awaiting me. When I began to appraise it, I perceived the quote to mean, creating yourself allows ownership to create and to communicate, whereas, if I were trying to find myself, I wouldn't be initiating any action. Its significance touched me personally to mean my seizing ownership through an incentive to create in the unique way of how I see things and communicate my ideas through my art images. I learned at an early age that drawing was a natural fit, a way to have fun exploring new experiences that came to life on paper, and it became my lifetime recreational outlet. As I begin to share my story, I'm taken back to my early attraction to art and the social impressions that have been influential.

Every child is an artist. The problem is how to remain an artist once we grow up.
~ Pablo Picasso

I began accumulating my childhood impressions during the 1950s, an assumed era of social tradition and conformity that most people embraced but which was not without rock 'n' roll and its social rebellions cropping up. Some, as an example, saw the personality Elvis Presley as a step-out-of-the-box threat during that time. I don't know how much of the era's influences actually stuck with me, but my childhood strategy was kept simple. It was: recreation, one day at a time. I was old enough to remember those TV shows 'Ozzie and Harriet'

and 'Father Knows Best,' that were classic examples of what could be described as cheery Norman Rockwell paintings with non-threatening humor, but, nonetheless, I could relate to them. Another TV show in particular featured artist Jon Gnagy where you could draw along with him as he was giving his step-by-step art instructions. After I demonstrated my interest in scribbling out drawings, I became the proud owner of the Jon Gnagy drawing kit.

Children are born naturalists. They explore the world with all of their senses, experiment in the environment, and communicate their discoveries to those around them.
~ The Audubon Nature Preschool

I grew up in New Jersey along the Jersey Shore, a short bicycle ride away from the ocean beaches and boardwalk activities. Without realizing again the influence of the environment's grandeur towards my personal growth, all that mattered was that it was my optimal playground. Summertime meant my divided time was shared with family and best friends, riding waves at Sea Watch beach, making 'spook trails' as we called them (mainly to scare our parents), building a simplistic tree house made up of one board to sit on with rungs leading up to it, and preparing mud patties to sell dirt cheap, the list goes on. My parents, who never met a roadside attraction or historical site they didn't like, would load up the car with all the necessary provisions for five and would turn our trip excursions into everlasting memories that have been logged into our family albums.

If you hear a voice within you say 'you cannot paint', then by all means paint and that voice will be silenced.
~ Vincent van Gogh

Our home sat on two acres and accommodated my grandparents' home situated right behind us. I remember watching my grandparents' preliminary sketches transform into beautiful landscapes, seascapes, and animal oil paintings that inspired me to add to my portfolio's scribbled drawings of 'stick people.' My grandparents' patience, their warm demeanor, plus their hunch to keep instructions simple, all point to their intuitive guess not to overwhelm me before getting started. They created the perfect setting that would benefit a kid's free expression. They laid out the paint brushes, oil paints, thinners, and a blank canvas and told me to 'create whatever I want, take as long as it takes, and have fun while doing it.' Their meticulous preparation in getting me started was as if they were setting up for themselves and this gave me a sense that they saw a potential talent that just needed to be discovered. As it turned out, that blank canvas became Niagara Falls – with little realistic similarity – but, nevertheless, my grandparents declared it a triumph and finished it off with a professional art frame.

In the Torchlight, cont. on page 43



COOKS' HAPPY HOUR

BY PENNI WISNER

'Tis the Season

If you thought you might find ideas here for creative openers for your holiday cocktail parties or potlucks, think again. Whenever I give a dinner and anyone asks: "What can I bring?" my answer is: "The hors d'oeuvres." Somehow, they strike me as fripperies, not real food. If fresh garden peas are in season, I simply put a bowl of them out for folks to shell and eat. For the rest of the year, I have very few ideas. And I don't want any hors d'oeuvre to compete for attention with the meal I have put a lot of thought into.

But. You knew a "but" was coming, didn't you? Little bites do serve an important purpose: They anchor that glass of wine, that Campari and soda, Negroni, or – is there a mixologist in the house? – one of the newfangled cocktails appearing at restaurants and bars all over town. Yours, too, I hope, as they can be delicious. I'm particularly fond of those based on prosecco. Oh, distracted again.

As good as Marcona almonds are, as addictive as the rice stick medleys with their explosive wasabi peas can be, we need to have something almost as easy as opening a bag but more elegant. And, if it were more healthful, too? Well, then, let's have another round.

Mushrooms fit the bill admirably. They are low calorie, good sources of fiber, and are good-to-excellent sources of vitamins and minerals. They have anti-inflammatory effects as well. (In my household, the two boys are both following anti-inflammatory diets.) To me, their most important attribute is that they are delicious and versatile in cooking. To be healthful and safe, mushrooms do need to be cooked, even those little white ones tossed raw into all the salads of my youth. Yet I survived. Now that we know better and are – so they say – older and wiser, we cook our mushrooms. Don't we?

So why don't we get on with it: Buy a half pound or more of brown button mushrooms. For the best look to the finished dish, choose tightly closed ones. (White buttons, brown buttons [also called crimini], and portobello mushrooms are all of the same category: *Agaricus bisporus*. In fact,

portobellos are large criminis.) Trim and wash them. Here's a trick I learned from a professional chef many years ago: Dunk and toss the mushrooms quickly and vigorously in fresh water, immediately drain them, and then scatter them on a large kitchen towel. Enclose the mushrooms in it by folding the long ends together. Now grasp the towel at each end and shake the bundle back and forth. Hopefully, the towel is securely closed or the mushrooms will fly out. If you are working ahead of time (which you need to), no one will be there to see. Gather the escapees and start over.

Now put a large, nonreactive saucepan on the stove. For a half-pound of mushrooms, add to your pan the juice of two lemons, a half cup of dry white wine, a half cup of good quality (meaning fresh, not rancid – we've talked about this subject as I recall) olive oil, a branch of thyme, oregano, or rosemary (or all three), a dab of tomato paste (since tomatoes are still in season, you can add a peeled, chopped fresh tomato, too), 20 whole coriander seeds, a pressed clove of garlic, and a big pinch of salt and some freshly ground pepper. Bring the mixture to a brisk simmer over medium heat and cook for a minute or two to meld the flavors. Add your washed and dried mushrooms and simmer them until tender, about 10 minutes. Let the mushrooms cool in the cooking juices, transfer to a bowl, cover, and refrigerate. You can eat them as soon as they have cooled but they will gain more flavor if made a day ahead of time. Serve the mushrooms at room temperature in a pretty bowl with a supply of toothpicks, or thread them onto skewers either alone or with strips of roasted red bell peppers, cherry tomatoes, and/or small balls of fresh mozzarella or a cube of Parmesan or Gruyère. A half pound of mushrooms should serve four to six. But holiday parties often involve crowds of people, so double or triple the recipe. They will keep for several days, if refrigerated.

It's a five-year anniversary for Cooks' Happy Hour, too. Thanks, Penni, for all those palate-pleasing and healthy foods and invaluable tips for marketing and preparation. Here's to many happy hours ahead!

Our motto: Eat Well to Stay Well



INTERNATIONAL SCENE

EDITED BY ANNETTE ABURDENE

MEETING OF EUROPEAN WM NETWORK

AFFILIATES: LONDON 2013

Six European countries were represented on March 16 at the EWMn annual board meeting that took place at the Royal College of General Practitioners in advance of the Fourth International Doctor/Patient Forum the following day. Also present were Dr. Robert Kyle of the Mayo Clinic, USA, and Marta Campabadal, who works for EURORDIS, Rare Diseases Europe, in Barcelona. With her colleagues, Marta manages RareConnect, a pioneering website that supports those affected by rare diseases. Forty online communities, including WM, are currently supported by RareConnect. Each community has an online discussion forum accessible in five European languages, as well as areas for posting stories, personal profiles, articles and information. Marta gave a vivid and informative presentation of the RareConnect “user experience,” including an overview of the multimedia elements available to the site’s communities and highlighting the important issue of online privacy.

The meeting focused on the two main strands of EWMn’s work, patient support and advocacy. Dr Kyle’s long experience with groups organized to promote both support and advocacy, especially with the IWMPF, was of particular value, and he was emphatic that activities oriented toward patients, their carers, and families were vital at all stages. Dr. Kyle spoke to the importance of local involvement to build a strong base among patients, carers, and professionals in order to deal with the challenges of advocacy. The point was powerfully made that successful advocacy would not be a mere matter of the size of our affiliated patient groups but would rest on strength of organization and a willingness to be assertive, even loud, in the interests of sufferers.

The Board’s next target is to concentrate on strengthening cooperation with those health agencies in Europe where it already has connections (Eurordis, ECPC, EMA). Key aims are the establishment of patient registries as well as the securing of clinical trials and new treatments within Europe.

Newsletter page at ewmnetwork.eu has links to the above presentations in 5 languages.

Phil Manning, WMUK, reporting.

FOURTH INTERNATIONAL PATIENT FORUM: LONDON 2013

Hosted by WMUK, the Fourth International Patient Forum was attended by around 150 delegates at the Royal College of General Practitioners on March 17. The program of participants, which Dr. Shirley D’Sa (UK) promised in her opening remarks would be “lively and interactive,” included speakers Dr. Helen McCarthy (UK) and Dr. Robert Kyle (USA) plus a panel consisting of Dr. Chara Kyriakou, Dr.

Roger Owen, and Dr. Guy Pratt (all UK) and Dr. Monique Minnema (The Netherlands). Discussion covered such topics as the promise of ibrutinib (now in clinical trial in the USA), life expectancy with WM, and prognostic indicators.

During breaks the participating clinicians were available for “Ask the Doctor/Nurse-Lite” sessions, where patients and carers could raise their own concerns directly, and many attendees took advantage of these valuable opportunities. “Patient Tales” were on display, giving contrasting snapshots of life with WM.

Sessions in the afternoon began with two presentations by Dr. Roger Owen, the first being on the upcoming R2W Trial in the UK (which will compare fludarabine, cyclophosphamide and rituximab with bortezomib, cyclophosphamide and rituximab as upfront therapy). In his second presentation Dr. Owen gave the first public airing – before official publication – of the new UK Treatment Guidelines for WM. Dr. D’Sa spoke next on “Living with WM” and emphasized that it is often a challenge for patients to find reliable information and to distinguish symptoms of WM from the general “noise” offered up by daily life. Here IWMPF, WMUK, and other organizations can be of help. A final session of questions to the physicians’ panel concluded the formal program.

A DVD of the Forum is available. See wmuk.org.uk for details.

Many thanks to our sponsors including the IWMPF, European WM network, and Eurordis. Without their support the success of the Forum would have been not been possible.

Phil Manning, WMUK, reporting.

CMWP (MM AND WM) PATIENT ASSOCIATION NETHERLANDS

On April 13 the patient association Contact Group Myeloma and Waldenstrom Patients (CMWP) held its annual symposium, attended by around 100 patients and their partners. The Dutch WM specialist Dr. Monique Minnema from University Medical Center, Utrecht, gave an interesting presentation of the present state of diagnosis and treatment. In the questions that followed, great interest was expressed in ibrutinib. Dr. Minnema explained that this drug is very promising. However, even if all goes well, it will take time before this medication will be available in Europe, since the necessary procedures are very lengthy.

Preceding the symposium was CMWP’s annual general meeting. A historic moment at this annual meeting was the decision to dissolve the thirty year old CMWP and to form a new hematological patient organization, Hematon. This new organization is a merger of all four existing Dutch hematological patient organizations: CMWP (MM &

International Scene, cont. on page 35



WM), SCL (leukemia), LVN (lymphoma) and CST (stem cell transplants). The reason for merging is the fact that all concerned are convinced that joining forces offers huge benefits to the patients and their families, particularly in the field of advocacy, innovation, and administration. However, all parties pledged that they will keep their own identity with respect to disease specific topics such as support groups, newsletters, and web sites. More information, in Dutch, at waldenstrom.nl

Marlies Oom, European WM Network, reporting.

WALDENSTRÖM FRANCE ASSOCIATION

The annual meeting of Waldenström France will be held on September 28, in Paris at the Plateforme Maladies Rares, Hôpital Broussais, 96 rue Didot, 75014. The speaker will be Dr .Véronique Leblond, highly regarded French oncologist specializing in WM and member of the IWMF Scientific Advisory Committee.

For program details and registration information please look at or contact portail.waldenstromfrance.org/reunion-de-lassociation-paris-2013 waldenstromfrance@live.fr
Tel: +33 (0)490 870 930.

Michel Houche, Waldenström France Association, reporting.

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

CALIFORNIA

Sacramento and Bay Area

Clear communication was the theme of the fall meeting at the Kaiser Hospital complex in Roseville. The group watched a video from the television program, "Second Opinion." The program focused on how to better meet health care needs by improving the communication between doctor and patient. Afterwards, the members exchanged news while sharing pot luck finger foods.

COLORADO & WYOMING

A sell-out crowd participated in the "Chat with the Expert" WM-focused breakout session and lunch that were part of the day-long April Leukemia & Lymphoma Society Rocky Mountain Blood Cancer Conference. Three hundred attended the Conference to learn about topics such as nutrition, how chemo works, caregiving tips, survivorship, and Medicare. Thirty-five WMers and 70 nurses and social workers were present for the support group meeting luncheon and presentation. Dr. Jeffery Matous of the Colorado Blood Cancer Institute presented recent research updates from Dr. Steven Treon of Dana-Farber Cancer Institute (DFCI). Both doctors were together in Kyoto, Japan, for a Multiple Myeloma Conference where WM was also covered. In addition, Dr. Matous reviewed the good results from local trials with bendamustine and Rituxan and the exciting results from the ibrutinib trials. Dr. Matous also covered the most recent findings concerning the MYD88 mutation and their possible impact on future targeted therapies. This third annual Conference and WM session was the fruit of a wonderful partnership with the local LLS chapter.

FLORIDA

North Central

Harriett Pawliger, a retired Licensed Mental Health Counselor, is starting a support group in the area for WM patients, friends, and family. Meetings will take place in Gainesville. Harriett obtained a degree in Occupational Therapy from the University of Florida. While studying there, she met David Pawliger, a medical student; they married and have three daughters. Their family now includes two sons-in-law and two grandsons. In 2011, Harriett and David celebrated their 50th anniversary. After working for many years as an occupational therapist, Harriett again enrolled at the University of Florida. In 1985 she received a Master's Degree



Harriet Pawliger

and a Specialist's Degree from Counselor Education and a Certificate in Gerontology from the Center for Gerontological Studies. She then joined a group practice and specialized in adult and aging issues. She also volunteered with the American Cancer Society and facilitated a breast cancer support group for several years. In addition, she has facilitated several other support groups, including a caregivers group. In 2009 Harriett was diagnosed with WM. Though she has developed some peripheral neuropathy, she remains on watch and wait. In addition to her local care, she travels to Boston once or twice a year to see Dr. Steven Treon at DFCI and participates in his genome study. Harriett very much looks forward to facilitating

Support Group News, cont. on page 36



this new WM support group. It will provide opportunities for members to share their experiences with this rare disease, to support each other along their journeys, and to gain more knowledge and information from experts via speakers, videos, and handouts. If you are interested in joining this group or would like more information, please contact: Harriett Pawliger at Harrpaw@aol.com or at 352-331-7340.

INDIANA

Sixteen WMers and their caregivers met in June at the LLS Indianapolis office. Claire Kammen of the LLS provided breakfast snacks and Starbuck's coffee. The relaxed ambiance led to comfortable conversation and sharing by all. The topic of fatigue had recently been batted around IWMTALK and was introduced to the group as a topic for exploration. Conversation, learning, and sharing were the themes for the day. After the discussion, the group watched Dr. Morie Gertz's DVD presentation, "Weeds in the Garden." Jenny Terry, a healthcare attorney, plans to discuss the upcoming changes to healthcare at the next meeting.

NEW ENGLAND

Boston

Representatives from DFCI, including Dr. Steve Treon and Chris Patterson, and all the support group members thanked **Lynne** and **Joe Mara** for their many years as the group's leaders and productive fundraisers for WM research and care. They

have passed the torch to **Jan** and **Jack Whelan**. These four friends would often connect at the meetings as well as in the infusion rooms and hallways at DFCI. Jack also expressed a very special thanks to **Judy Christensen**, who has been an important contributor and part of the group's leadership from the outset. Jack Whelan, transitioning from his career as an IT research analyst to "research advocate," has been active in IWMTF as a volunteer photographer, as a fundraiser



Jack Whelan

pursuing bio/pharma companies, and as a session and keynote speaker at IWMTF Educational Forums and for the LLS, where he is a legislative advocate. He may be familiar to many WMers from his photography of seven (so far) Ed Forums (see Jack.Whelelan.com/video/San_Diego). Jack is an associate member of the American Association for Cancer Research (AACR), completing the 2013 Scientist-Survivor program; he is active in the American Society of Clinical Oncology (ASCO), completing the Research Advocate 2013 Scholar program; and has a 2013 Patient Advocate Fellowship with the Drug Information Association (DIA). His wife Jan and three daughters – Laurie, Patti, and Karen – volunteered at

the Ed Forum in San Diego and will help with support group activities, too. Grateful for this opportunity to give back, Jack believes that as WM becomes a manageable blood cancer resulting from the new treatment options, optimism and fun are key ingredients of any treatment plan.

NEW MEXICO

Ginny-Kay Massara is in the process of organizing a group for New Mexico. Although born and raised on the East Coast, Ginny-Kay moved to New Mexico in 1961 to get a degree in anthropology and never left the state. She has three children,



Ginny-Kay Massara

nine grandchildren, and two step-grandchildren. Ginny-Kay retired as a paramedic and firefighter but not from school. She is currently finishing a Ph.D. in Archeology and Biblical History. Ginny-Kay plays guitar for her church praise group, crochets, and works on genealogy, as well as several hundred other hobbies put off until "retirement." She was diagnosed with WM in 2010 and is currently being treated with rituximab and IV gamma globulin. She would

love to hear from any WMers in New Mexico or neighboring states and can be reached at: ginnykay1@juno.com

NEW YORK

New York City

Dr. M. Lia Palomba of Memorial Sloan-Kettering spoke to the metro area group in May. Dr. Palomba has a special interest in WM research and accepted Dr. Treon's invitation to run a wing of the much-talked-about ibrutinib trial at Memorial. More than 50 patients and caregivers crowded the meeting room, eager to hear more about ibrutinib, now available locally to New Yorkers through this trial, and also more about Sloan-Kettering, which previously had not appeared to focus on WM. Dr. Palomba was exceptionally impressive, knowledgeable, and compassionate. Not only did she charm everyone but, despite having given up a Sunday afternoon for the presentation, said she would be delighted to return. Participants left the meeting smiling and encouraged by the broadened interest in the City for our rare condition and the exciting promise of new and safer treatments.

Eastern NY/Western New England

Once again **Kay** and **Tom Zolezzi** opened their amazing home for the annual summer picnic in August. It was a perfect day (sunny and mild) for enjoying their backyard with its pool and vast array of flowers, herbs, and spices

Support Group News, cont. on page 37



(with identification markers!). Joining in the day were **Mary Ughetta, Thad and Sylvia Raushi, Sandy and Kent Solomon, and Mel and Sissy Horowitz.** Widely ranging conversation (including politics, the weather, summer vacations, education policy, and, oh yes, even WM!) was sandwiched between appetizers (marinated shrimp and fruit, chips with pineapple salsa), beverages, vegetable quiche, lasagna, chicken with mushrooms, pasta salad, chicken salad with rice and grapes, and Kay's famous cookie/ice cream sandwiches for dessert. The fall meeting will focus on the role religion might play when patients face a serious medical condition. The speaker has both medical and church positions. Not to be missed: the Holiday Party on December 7. Anyone who is in the Albany, NY, area is welcome to attend the events.

Rochester, Western and Central NY

The group gathered for lunch in the spring and fall. Those who attended are in reasonably good health; one has been in remission and off chemo for over 11 years. Another is on watch and wait, even with an IgM level of over 2000 mg/dL. In discussion, the group surmised that this appears to be the trend: oncologists do not recommend treatment unless the patient exhibits some serious symptoms of WM. The other trend members notice is that treatment protocols have changed a great deal and for the better. Now members needing treatment usually receive multiple-drug therapies – especially Rituxan plus one or more of the newer chemotherapeutic agents. Long-timers in the group had been treated one drug at a time until something worked.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

A beautiful library in Independence, OH, was the location of the recent meeting. An unusually large turnout of WMers and support people gathered for sharing and education. **Peter DeNardis**, known by the WM community as our awesome IWmf-TALK manager, gave a comprehensive overview of the Patient Database with handouts for future reference. Pete's presentation stimulated much discussion and thoughtful ideas. Group sharing offered members the opportunity to feel connected and at the same time appreciate the unique differences in personal WM stories. All enjoyed an abundance of delicious refreshments, including a great deli tray and healthy selection of fruits. Plans are to alternate meeting locations between Pittsburgh and Cleveland in order to accommodate more of our group members.

OREGON/SOUTHWEST WASHINGTON

In the supposedly rainy Northwest, it was a beautiful, sun-filled day when the group met in July. Twenty-six members greeted Christopher Yasenchak, M.D., who discussed "Current



Eastern Ohio-Western Pennsylvania group members met in the Independence library to hear details of the Patient Database from Peter DeNardis (Pete stands fourth on the left).

Perspectives: Waldenstrom's Macroglobulinemia." Dr. Yasenchak specializes in medical oncology with an emphasis in cancers of the blood, lymphoma, myeloma, and intestinal disorders. He is currently Research Co-Medical Director of Compass SWW Oncology and came to Oregon from a residency and fellowship at the Mayo Clinic in Minnesota. After an introduction in which he categorized non-Hodgkins lymphomas, Dr. Yasenchak went on to address the emerging therapies for WM and other types of lymphomas. He discussed the use of old and new drugs and drug combinations for different phases of WM, for example, first-time treatment and treatment of relapses. He described the next generation of targeted therapies and showed which cell markers they address. He also described the differing phases of clinical trials, how they work, and where some of the newer drugs are in the trial process. During Dr. Yasenchak's informative and encouraging presentation, his excitement about the progress in treatment of lymphomas was evident, as was his concern for those of us dealing with blood cancers and his passion to find better tools for treatment and cure in the years ahead. The group was delighted to have some new members, including two couples from central Oregon, attend this important meeting. At the same event, **Joan Berglund** resigned her leadership of the group after seven years of service. Joan had the vision to found the group years ago and has been devoted to its growth and stability since. The local LLS partners with the IWmf to support the group, providing meeting locations and lunch, as well as assistance with publicity. Sue Sumpter, LLS Patient Services Coordinator, is a continuing, generous supporter. The next meeting is planned for October 26, noon to 2 pm, at the Fairfield Inn and Suites, 6100 SW Meadows Road, Lake Oswego, OR (very near the junction of I-5 and Rte 217).

PENNSYLVANIA

Harrisburg Area

Don and Kate Wolgemuth again hosted the summer indoor potluck picnic. Everyone enjoyed the food and conversation so much that the event ran an hour over time. Fewer members came this year due to some illnesses. The group hopes to

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A happy crowd gathered at the Harrisburg annual summer indoor potluck picnic. From bottom left: Liz Shearer, Kate Wolgemuth, Terrie Eshleman, Betty Wilt, Robin (Betty's daughter), Roberta Neill, Darwin Eshleman, Lois Eshleman, Fran Wida, Connie Wida, Don Wolgemuth, Mike Shearer.

welcome them and new members to the November gathering. The meeting frequency of the group has changed to three times per year: April and November on the second Sunday from 2 to 4 pm in Messiah Village's Board Room, plus the August picnic, which will continue but the location may vary.

SOUTH CAROLINA

Dr. Robert Stuart discussed advances in WM research and treatment with the group in Charleston this past spring. Dr. Stuart is Professor of Medicine, Hematology/Oncology at the Medical University of South Carolina (MUSC). He



Dr. Robert Stuart spoke in Charleston to an eager audience about the significance of the very latest results in WM research.

also treats several of the WMers in the support group. Dr. Stuart provided an informative summary of Dr. Treon's discovery of the mutated gene, MYD88 L265P, found in tumor cells of over 90% of WM patients. The presence of the MYD88 mutation impacts the signaling pathway which drives the growth of WM cells. Dr. Stuart also spoke

to the group about ibrutinib, the investigational oral agent developed as a treatment for lymphoma, which recently received Breakthrough Therapy Designation for WM by the FDA. Although we have been reading about these significant advances in the *Torch*, it was refreshing for group members to be able to have an interactive dialogue with Dr. Stuart. He also highlighted the major phases of clinical trials, which was of much interest to one of our members who is about to join one, and gave a brief synopsis of the pros and cons of several commonly used treatments for WM. Thanks to **David** and **Donna Orner** and **Sue Herms** for coordinating Dr. Stuart's visit to the support group meeting. At the fall meeting in Columbia, support group members met in an informal setting to exchange information and share experiences.

TEXAS

Dallas & Northern Texas

In the spring, support group member **Judy Francis** told attendees of her experience with an autologous stem cell transplant (ASCT). Judy received her transplant in the fall of 2012 and is doing well. She offered a very insightful look at planning for and surviving a transplant, including some tips and information not found in "the literature." In July, our group honored two of our ardent supporters with acknowledgment of their support and donations to the IWWMF. **Dr. Marvin Stone** was presented with a medicine-related stamp panel designed and created by group member **Phil Yedwab**. It features mounted postage stamps of historic events and physicians with a description of each underneath. The group also made a contribution to the IWWMF Research Fund in his honor. Besides being active in the IWWMF for many years, Dr. Stone has been a great supporter of the group, helping to arrange speakers as well as being a speaker himself. **Pam Carnevale**, who helps organize our meetings at Baylor Hospital in Dallas, was presented with a framed certificate of appreciation. Additionally, a donation to the IWWMF Member Services Fund, which supports the Foundation's operations (everything except research), was made in Pam's honor. Pam is the manager of the Cvetko Center for Cancer Support and Education at Baylor. She supplies everything from coffee and name tags to most of the guest speakers. The group is grateful to have the local support of Baylor Dallas and the Cvetko Center. After a summer break, meetings resumed in September. It was good to see everyone and catch up on news. For the educational program, the group watched the Ed Form DVD of Dr. Treon's MYD88 presentation.



IWMF TRUSTEES 1998-2013

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The current IWMF Board of Trustees at their November meeting in Sarasota. At far left is visiting guest Arlene Hinchcliffe, President of the Waldenstrom's Macroglobulinemia Foundation of Canada. IWMF Board Members and Officers, from left to right are: Michael Sesnowitz, Marty Glassman, Sue Herms, Cynthia Ruhl, Don Brown, Robert Kyle, incoming President Carl Harrington, outgoing President Judith May, Tom Myers, Elena Malunis, Peter DeNardis, Guy Sherwood, Marcia Klepac, Ron Yee.

1998-1999

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Former President
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2003

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2004

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 Dick Weiland, MN
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2008

Bill Paul, TN
 *Don Brown, IL
 *Peter DeNardis, PA
 Cindy Furst, CO

2009

*Marty Glassman, CA
 *Sue Herms, SC
 *Guy Sherwood, IN

2010

*Carl Harrington, PA

2012

*Elena Malunis, NY
 *Cynthia Ruhl, CA
 *Marcia Klepac, PA
 *Michael Sesnowitz, VA



compromised. This is why investigators and research sites are screened for experience prior to being selected to participate in a clinical trial. Clinical trials require extensive specialized testing and careful monitoring. Also, the research nursing specialists, research pharmacy requirements, and specialized laboratory and testing equipment may only be available at specific research centers.

The new Blood Cancer Research Partnership will test whether trials can be done safely in smaller settings with practitioner/researchers in order to reach more patients not able to travel to big academic centers. This type of program may be particularly important for rare diseases where no center has enough patients to perform a trial. This concept may have the benefit of bringing more “real world” patients onto clinical trials, but it also runs the risk of having trials stopped too soon due to the inexperience of investigators and staff. This novel program will be watched closely as a new model for the future.

Do drug companies perform trials with drugs they know aren't good?

Given the extraordinary costs of drug development and the goal of getting approval and recuperating costs of development and research, there is no incentive for a company to start a large Phase 3 trial without a reasonable belief in its success. Also, this decision is only made after careful scrutiny of Phase 2 data, in discussion with regulatory authorities. Lacking promising Phase 2 data, companies favor saving money by stopping development or making new adjustments rather than initiating a Phase 3 trial for approval. Often this cost/benefit analysis has meant that drug developers have chosen to proceed with Phase 3 trials primarily in larger indications (more prevalent diseases) that have a greater market potential. However, with the recent trend to more specific and targeted therapy, this model is changing.

How can rare diseases be better represented?

New models of clinical trial participation, including cooperative groups, consortia, and clinical trial networks through disease-specific advocacy groups, are ways to provide access to new drugs for patients with rare diseases. Regulatory incentives such as *Orphan Drug Designation* may also provide a stimulus for researchers to study rarer indications. Incentives for sponsors include grants and

guidance for clinical trials. This program is particularly designed for treatments of diseases/disorders that affect fewer than 200,000 people in the U.S., and thus are not expected to recover the costs of development and marketing.

What are the FDA and other health authorities doing to improve the drug development process while maintaining safety?

The FDA has several new programs to help speed promising agents through development. One program, *Breakthrough Therapy Designation*, is intended to expedite development of drugs for serious or life-threatening conditions. A Breakthrough Therapy Designation requires preliminary clinical evidence that the drug may have substantial activity. If a drug receives this, the FDA has an organizational commitment to work with the sponsor to get the data necessary for approval as efficiently as possible.

Accelerated approval is intended for drugs that demonstrate an effect on a “surrogate endpoint” that is reasonably likely to predict clinical benefit and that can be measured earlier than an effect on survival. Accelerated approval may require additional trials after approval, and approval can be withdrawn if the benefit is not verified.

Priority review was initiated as part of the Prescription Drug User Fee Act (PDUFA). If a drug receives a priority review, the FDA agrees to complete the review and act on an application within 6 months rather than the standard review timeline of 10 months.

FINAL THOUGHTS

Drug development is undergoing dramatic change. As we understand the biological differences between patients with the same disease and the biological differences between individuals, our approach is becoming more patient specific rather than disease specific. This poses a new set of challenges for research scientists and requires new paradigms for drug development and approval. Novel ways to conduct trials, new endpoints for success, new ways to collaborate, and new regulatory processes are just the start. It is an exciting time for clinical research. Should you participate? For each individual it is a risk/benefit question. For those of us involved in drug development, we hope that for many patients the answer will be yes.



location for the Foundation, with a salaried person to run the office and be the initial contact person. Our amazing Sara McKinnie came along – bright, comforting, efficient, and also tireless.

I won't say we all agreed on everything all the time. We learned Robert's Rules of Order on how to conduct business meetings, how to achieve consensus. We were learning by the seat of our pants. But always, our goal to have the best quality of life within this disease kept us on track, sharing our information and empathy with others, comforting and giving hope.

When the Board met, we made use of every minute of our time. Though the plan was for meetings during the day, then time for dinner and relaxation, we all wanted to meet late into the evenings. Nothing was more important than growing our organization!

Ben Rude became the Vice President and could step in to any situation requiring the President as needed. As every single Board Member filled an essential need, we could hardly hold ourselves back from devoting our lives to this organization. We could see the progress. We developed professional publications to share our growing knowledge with doctors and patients alike. We evaluated and funded research. We watched our efforts reap rewards for us all.

Laurie concludes:

Arnie was a very energetic, determined man. He was a bulldog when it came to doing all he could for the cause of helping people with WM. He spared no effort or expense in aiding those who needed information and encouragement.

Every fledgling organization would be fortunate to have Arnie Smokler to get it started!

could barely hear and could only see silhouettes. I had an enlarged heart, an enlarged spleen, an enlarged kidney, and swollen lymph nodes. Finally someone believed me when I said I was sick.

So began a whirlwind of activity: more units of blood, oxygen, and installation of a Quinton catheter for the first of many plasmapheresis treatments. A couple of days later, Dr. Fisher said, "Welcome back to the living." Those words have stayed with me since. It wasn't until two weeks later that I found out he had called my family on the East Coast to say that if they wanted to see me one last time, I had maybe two days to live.

Several weeks later and facing massive medical bills, I applied for Medi-Cal. Dr. Fisher wrote a short letter explaining my condition. The last sentence I will never forget: "His prognosis is grim."

Thus began my tumultuous journey toward healing. Over the next several years, I endured one day at a time. I had two courses each of fludarabine, 2CdA, and Leukeran. My IgM bounced around but never dropped much below 8,720 mg/dL. I went to the emergency room at least once a month with full-on, nonstop nosebleeds, bone-crushing pain in my upper left thigh (remember watching cartoons and one of the characters would get smashed and a circle of stars and planets would circle his head? Well, I am here to tell you, that really happens), and infections (the fastest time from my normal body temperature to "help" was forty-five minutes. I hit 105°F a couple of times and 104°F several more times).

I was admitted to the hospital at least seven times, not including twice in the bone marrow ward intensive care unit. Most hospital stays were for a minimum of three days to as long as seven days.

My most common daily irritant was lack of mobility. It felt like my body was in a slow state of decay. My strength was drained, and I was so weak I needed a cane to walk. Every step I took was calculated. I was constantly in pain and lived in fear of falling.

One of the meds I took was prednisone. One day while resting, I felt a twinge and a sudden burst of warmth in my left thigh. By the end of the day, my leg had swollen to twice its normal size and ached constantly. Off to the hospital I went. A major artery had ruptured. One possible cause was the prednisone: a potential side effect of long-term use is the thinning of blood vessel walls.

Because of weakened muscular strength, my spine became compressed, aggravating an old injury. I was hospitalized and treated several times for degenerative disk disease. Diverticulitis, another symptom related to WM, also took me to the hospital.

Survival tip: If you are experiencing episodes that may send you to the hospital, I have found it beneficial to document symptoms (timeline, intensity, etc). If you should happen to end up in an emergency room, you may not be lucid enough to give many details. For critical treatment, time is of the essence, and the less the doctor has to guess about, the better for you.

It wasn't until I was put on plasmapheresis for "the rest of my life" that the symptoms subsided. Dr. Fisher commented that if he could keep me alive long enough, there were new treatment protocols on the horizon. (Thank you Dr. Treon and the other WM researchers.) After two years of plasmapheresis at least once a week, my IgM was down to as low as 7,000 mg/dL with only minor occurrences of infection and fever.



On occasion my IgM would dip below 4,000 but it never stayed there long.

The decision to write here about my near-death experience has caused me some anxiety. The emotional and moral conflict caused by facing my mortality was very personal, and I have only talked about it with a few close friends. My struggle affected not just me but all those close to me. To those who may be uncomfortable with what follows, I deeply apologize. But I speak to those who may find comfort in my experience.

For the initial 18 months to two years after my diagnosis, I was in a critical state. Death became my companion, always close enough to touch. As time went by I came not to fear death but to see it as a comfort, a friend, a release from the agony I endured every day. There was no clear prognosis of survival so why go through this living hell? I was delirious from so many drugs and procedures that I often thought of suicide. Several times I fell asleep at night with my hand on my catheter tube; just one turn and I would bleed out. Everyone would think it was an accident. So why not? I asked myself this question often, and yet each day I found a spark of hope from those who prayed for me and had enduring love for me. I fought to survive, if not for myself, then for them.

During this period, I had four near-death episodes. In hospice care there is the phrase: "A person is actively dying." Actively dying is when the body's organs and life processes start to shut down. I remember the moment I entered this state for the first time. I was in the hospital being treated for one of my many episodes, hooked up as usual and alone in my room. Slowly I noticed this odd feeling of loss of control. I could no longer feel my body; I was no longer in pain. I felt light and drifting, a sense of almost falling. My eyes became fixed, looking straight up. I could not move and lost awareness of my physical body. I heard the machines beeping in the background and some sort of commotion. My attention was focused on my inner awareness. I began drifting inwards, slipping down a long tunnel. A feeling of calm came over me and also of confusion. Oddly enough I was fully conscious and in tune with every passing moment. Something unique was happening to me, and I wasn't sure I was going to like it. Was I having an out of body experience? I was keenly aware of a "different" environment. I realized how precious life is and that I wasn't ready to go yet. Then suddenly I was snapped back into the room, and Dr. Fisher was looking directly into my eyes. Again came those words: "Welcome back, I thought we lost you."

The next moment I felt overcome by searing pain so intense it caused delirium and hallucination. My body was not happy that I had returned. Now it had to "reboot." The excruciating pain made me question the decision to live. But I was here and this was the price I paid to return. A day or so later, as I reviewed the event, I realized the gravity of what my doctor had said. I recognized that I had experienced a significant spiritual event. The impact of that moment has forever

changed me. No longer do I take each day, each moment for granted. It was during one of these times that I commented to a friend of mine that I discovered the meaning of Life... breathing. If you are breathing it means you are still alive!

Time went by as I continued to fight against the cancer but to no avail. With no other options, I joined a clinical trial in which participants underwent two stem cell transplants (autologous) within a single year. The first was in November of 2000 and the second was in June of 2001. The first transplant lowered my IgM from around 8000 mg/dL to near 5000. The second lowered it to 1900. My IgM got as low as 1200 and has been slowly rising since then. My sight, hearing, and stamina improved greatly – not to pre-diagnosis levels but enough to regain my "normal" activities. Since the twin transplants, I have not had any other chemo treatments. I have also never been "cancer free."

I maintain optimum health with good nutrition (I eat a gluten-free, dairy-free diet, and my brownies are beloved by my IWmf support group), exercise (I don't backpack as much as I used to but often take day hikes in the high country), and plenty of rest. I normally take a couple-hours nap most every day. I have learned the hard way that the quickest way to upset my fragile immune system is from exhaustion.

Presently and unfortunately, there has been a dramatic spike in my IgM level. Within a couple of months it rose to 4,400, high enough and fast enough that Dr. Fisher was contemplating "aggressive chemo" again. I wasn't happy to hear those words. Then, as suddenly as it rose, my IgM dropped to around 3600 and leveled off. I am considered to have an active cancer again and am looking for input on the experiences others have had with the new treatment protocols available today. I may need one or two choices in the near future.

After spending all that time in the care of others, I developed a strong sense of compassion for those in similar situations. For the past ten years, I have been involved in the healthcare industry as an in-home caregiver and hospice worker. I meet many wonderful people, and I find it very rewarding being able to do for them what was done for me. I especially find hospice uplifting. I have had profound experiences with many who are comforted by my ability to listen to what they are going through without being judgmental.

There are not enough words to express the gratitude and appreciation I have for the doctors and staff at Sutter General Hospital for the years of care they have devoted to keeping me alive. There were so many questionable moments, but they did not give up on me and neither did I. I am indebted to my many dear friends and family who held me close in their hearts and prayers. Many were personally and intimately involved in my care. Every day since then has been a gift that I am truly honored to have. I awake each day and accept what



is to be. I have no bad days. If I can get out of bed there are good days and better days. I endeavor to be a benefit to others. It is the least I can do.

Life is a blessed gift. Death is a profound transition. The eternal questions have always been what happens next and

are we aware of it? I no longer ask those questions. Never give up, but when the time is upon you, surrender with grace.

Many thanks to Penni Wisner for her helpful suggestions in composing this article.

Eugene Turner can be reached at: eugene29t@yahoo.com

have a sufficient impact on patients to justify therapeutic intervention. When Waldenström causes enlargement of the liver and/or spleen, although this occurs but rarely, it can reach a level where patients actually develop abdominal discomfort. If this interferes with their quality of life, therapy would be justified.

There are several manifestations associated with IgM monoclonal proteins that justify therapy, even when there is no problem with anemia, low platelets, enlargement of the liver and spleen, weight loss, etc. A small proportion of patients with an IgM protein can develop systemic amyloidosis. Systemic amyloidosis is, fortunately, a rare complication of IgM proteins and Waldenström. But because it is a serious disorder, most patients require therapy even in the absence of symptoms because the amyloid can cause damage to vital organs. Rare patients with IgM proteins can develop cold agglutinin hemolytic anemia or cryoglobulinemia, which also do not have as benign a course as Waldenström

macroglobulinemia and require early intervention to prevent serious end-organ complications.

The management of the “watch and wait” patient is a partnership between the patient and the patient’s physician. Sometimes this is an excellent scenario for a second opinion to provide guidelines in case the oncologist has a limited experience with Waldenström. The input of an experienced medical center often helps to define the monitoring endpoints in order to arrive at an appropriate conclusion.

In summary, some of the signs that indicate the need for treatment of Waldenström macroglobulinemia include: anemia, hyperviscosity, lymph node enlargement and marked enlargement of the liver or spleen. The associated symptoms would be: fatigue, shortness of breath with exertion, palpable lumps, nose or gum bleeding, unexplained weight loss or fevers. Keep in mind that there is no threshold above which the IgM level mandates the initiation of chemotherapy.

Without a doubt, my grandparents’ close proximity gave me another set of caring mentors who prodded me to continue to do what made me happy all along.

A lot of my life happened in great, wonderful bursts of good fortune, and then I would race to be worthy of it.

~ Julie Andrews

From those yesteryears, I knew early on I was born under a lucky star, living amongst a family of creative individuals who stimulated my impressions and that gave me a happy and a secure start. Drawing has accompanied me through many personal interactions and the result is that I have this expectation: drawing won’t abandon me and will be there whenever I call upon it. It opened doors to unexpected art projects in the workplace beyond the routine duties of my provisioning career; it partook in times of celebration, special

occasions, and it now has transcended beyond my WM diagnosis in 2007. In hindsight, those simple instructions that I heard years ago to ‘create whatever I want, take as long as it takes, and have fun while doing it’ turned out to be a sound philosophy and one I continue to work on today with enjoyed results.

See yourself as “Us” and you will never be alone.

~ Unknown

Through the help of my wonderful husband Bill, my entrusted oncologist and staff at EvergreenHealth and Seattle Cancer Care Alliance at Halvorson Cancer Center – and with the devoted efforts from the IWMF to provide patient and research support – anything is possible.

Never, never give up.

~ Winston Churchill



**SINCE MARCH 2013, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

Bernie Admire

Earl Nolting

Eddy Andersen

Bob Andersen

Iona Anderson

Gary & Sharon Dionne

Audrey Thompson

Irene Anderson

Tim & Lillian Faubert

Order of the Eastern Star – Elliot Lake

Ilona Stewart

Stacey Verbonac

Gerry Young

Patti Arn

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John Austin

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William Kelley

Carl Larson

Ethel Balansoff

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Gail Desharnais

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Harry Edward Connors (cont.)

Ed Kavetsky

Jason & Jennifer Connors Kavetsky

Jack Klawitter

Tom & Kathleen Matuska

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Al & Michele Roberts

Mr. & Mrs. William Rosenhamer

Walter Dere

Laura Dere

Scott Doran

Larry & Verna Ellis

**Ron Draftz and in tribute to all the
people who have Waldenstrom's**

Bob Andersen

Angelique Draftz

Germaine Draftz & Family

Andrew Warden

Pauline DuWors

Jeff & Helen Udell

Jean Ellis

Ray Ellis

Fred Fischer

Bob and Lynn Behrendt

David & Diane Birk

Lisa Outland Burns

Bert & Myra Fischel

Lawrence & Marsha Fischman

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Javier Gonzalez

Philip Goodman

Gary & Harriett Hoffman

Susan Hoffman

Tom & Shannon Hofner

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Milton & Joan Loeb

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Steve & Alyce Pine

Murray & Hazel Pizette

Wally & Sue Roberts

Peter & Judy Salzer



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Julie Stone
Toby Stone
Carol Swartz
Harry & Joan Swillinger
Loren & Andrea Weinstein
Phil & Diane Yedwab

John Flanzer

Gloria Flanzer

Janet Garfield

Merle Weston

Willard Gilson

Diana Gilson

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Virginia Hanson

John Hlady

Ken & Maureen Hlady

Eva Hasch

Linda Adams

Margaret (Peggy) Hawley

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Scott Beckman
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Mary Brown
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Paul & Ruth Morimoto
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May 16 - 18
Tampa, Florida

The 2014 Ed Forum will be held at the Renaissance Tampa International Plaza Hotel.

Look for details in the next *Torch*.