

INSIDE THIS ISSUE

Survivorship in Cancer.....	1
President's Corner	3
Peter DeNardis Honored	4
Ron Draftz Remembered	5
Research Update	6
The 2011 IWMF Matching Gift Program	7
The Minneapolis Ed Forum	8
What Is The European WM Network?.....	14
Medical News Roundup	16
Cooks' Happy Hour ...	18
From IWMF-Talk.....	19
Support Group News	21
International Scene ...	23
The "New" Website ...	25

SURVIVORSHIP IN CANCER

BY GUY SHERWOOD, M.D., IWMF TRUSTEE



*Dr. Sherwood at the recent
IWMF Forum.*

The WM cancer patient community has benefited from steady improvements in cancer treatments over the past decade, resulting in increased longevity for many patients. In fact, the view that cancer is a chronic illness is now widespread. The term “cancer survivor” was adopted some time ago to reflect this increased longevity. A number of organizations such as the National Coalition for Cancer Survivorship (NCCS), the American Society for Clinical Oncology (ASCO), the Institute of Medicine (IOM), the Lance Armstrong Foundation, and even the Centers for Disease Control and Prevention (CDC) have now agreed to a common definition (with some minor variations) of cancer survivor. Simply put, an individual is considered a cancer survivor from the time of diagnosis and throughout the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore considered “cancer survivors.”

With increased survival come repeated courses of chemotherapy and/or immunotherapy and associated long-term problems. The term “cancer survivorship” was coined to acknowledge the multitude of varied physical and emotional experiences faced by cancer survivors. Cancer survivorship encompasses the physical, emotional, and practical matters faced by patients, families, and caregivers from cancer diagnosis through the remainder of life.

In future issues of the *Torch* I will discuss some of the more common obstacles faced by WM patients as they navigate their journey into long-term cancer survivorship. In this article I begin with the topic of “chemo brain.” Subsequent articles will cover cancer fatigue, accelerated skeletal bone problems, neuropathy, depression, and other topics implied by cancer survivorship.

CHEMO BRAIN

Individuals with WM are living longer due in large part to much improved treatments. As a result many patients will endure repeated courses of chemotherapy over time. It is also becoming increasingly clear to patients and physicians alike that there are associated long-term side effects

that may accompany life-prolonging treatments. One of the vexing side effects that accompany long-term cancer survivorship is the poorly understood condition called chemo brain. Physicians refer to the symptoms of chemo brain as **cognitive deficits**.

cognitive: from *cognition*, “the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.”

deficit: “deficiency or failing, especially in a neurological or psychological function.”

Many of us have at times experienced what can only be described as a mental “cloudiness” or a mental “fog” before, during, and after chemotherapy. Although the exact cause of this cognitive dysfunction, which may be either temporary or permanent, is not always known, chemo brain is now an accepted and acknowledged phenomenon. The term chemo brain may be somewhat misleading however. We do not yet know with certainty that chemotherapy is the cause of concentration and memory problems in cancer survivors. An increasing number of studies are now underway to try and uncover how cognitive impairment occurs in cancer survivors and how modification of chemotherapy drugs and protocols may prevent it.

Survivorship in Cancer, cont. on page 2

OFFICERS & TRUSTEES

FOUNDER

Arnold Smokler

PRESIDENT

Judith May

SECRETARY-TREASURER

Bill Paul

VICE PRESIDENTS

Tom Myers, Jr.

Marty Glassman

BOARD OF TRUSTEES

L. Don Brown

Peter DeNardis

Cindy Furst

Carl Harrington

Sue Herms

Robert A. Kyle, M.D.

Guy Sherwood, M.D.

Ronald Yee

BUSINESS OFFICE

Sara McKinnie, Office Manager

IWMF SCIENTIFIC

ADVISORY COMMITTEE

Robert A. Kyle, M.D., Director
Mayo Clinic

Stephen Ansell, M.D.
Mayo Clinic

Bart Barlogie, M.D.
University of Arkansas

Morton Coleman, M.D.
Weill Cornell Medical College

Meletios A. Dimopoulos, M.D.
School of Medicine,
University of Athens, Greece

Christos Emmanouilides, M.D.
Interbalkan European
Medical Center, Greece

Stanley Frankel, M.D.
Columbia University

Morie Gertz, M.D.
Mayo Clinic

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

Eva Kimby, M.D.
Karolinska Institute, Sweden

Véronique Leblond, M.D.
Hôpital Pitié Salpêtrière, France

James Mason, M.D.
Scripps Clinic

Gwen Nichols, M.D.
Hoffmann-La Roche, Ltd.

Alan Saven, M.D.
Scripps Clinic

Steven Treon, M.D.
Dana-Farber Cancer Institute

Mary Varterasian, M.D.

Donna Weber, M.D.
M.D. Anderson Cancer Center

Survivorship in Cancer, cont. from page 1

What is chemo brain?

As noted above, physicians and neurobiologists refer to the effects of chemo brain as cognitive deficits or declining neuropsychological functioning. Some define chemo brain simply as mild cognitive impairment. Cancer survivors themselves describe changes in memory such as difficulty remembering common words (finding the right words to finish a sentence), trouble remembering details (names, dates, important events), short attention spans ("spacing out"), trouble concentrating (difficulty focusing on what one is doing, taking longer to finish things), difficulty learning new skills, difficulty multitasking, decreased ambition, confusion, and even mental fatigue associated with receiving chemotherapy treatments for cancer. Within one year of treatment, most cancer survivors will find that the cognitive impairments have greatly improved. For some patients, however, chemo brain can continue for years following completion of treatment. The estimated incidence of chemo brain is controversial and varies between 15% and 70%.

What causes chemo brain?

Neuroscientists now believe that chemo brain can be classified loosely as short-term chemo brain and long-term chemo brain (more than one year after treatment). Newer studies have demonstrated a number of causes for chemo brain, particularly for the short-term chemo brain symptoms. One must realize that some patients have very real cognitive problems irrespective of their malignant disease (pre-existing Alzheimer's disease, for example), whereas others may develop brain problems in the absence of chemotherapy treatments. Many cancer patients can develop cognitive difficulties as a result of hormonal manipulations for their illness (examples cited are estrogen blockers for breast cancer or androgen deprivation therapy for prostate cancer). For some patients, pre-existing cognitive impairment (Alzheimer's, vascular dementias) may be exacerbated by treatment with chemotherapy (and/or radiation therapy). It has been recently suggested that some individuals may have an inherited susceptibility to chemo brain.

The exact causes of long-lasting chemo brain are unknown. There are nonetheless a number of very treatable medical problems that can temporarily mimic chemo brain in patients undergoing chemotherapy: anemia (low blood counts); nutritional deficiencies; treatable illnesses (such as diabetes or high blood pressure); situational stress; emotional problems (depression and/or anxiety); fatigue and sleep disturbances; medications other than chemotherapy (pain medications, for example); changes in hormone levels resulting from some cancer treatments.

Cognitive impairment in cancer survivors may also be as a direct result of cancer treatments: chemotherapy; immunotherapy; radiation therapy (particularly to the brain); high dose chemotherapy and stem cell transplants as well as graft versus host disease

Survivorship in Cancer, cont. on page 24



The IWMF Torch is a publication of:

International Waldenström's Macroglobulinemia Foundation

3932D Swift Road • Sarasota, FL 34231-6541

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

E-mail: info@iwmf.com • Website: www.iwmf.com

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

PRESIDENT

Judith May

EDITOR

Alice Riginos

MEDICAL NEWS EDITOR

Sue Herms

SENIOR WRITER

Guy Sherwood

SUPPORT GROUP NEWS

Penni Wisner

IWMF-TALK CORRESPONDENT

Mitch Orfuss

CULINARY EDITOR

Penni Wisner

LAYOUT

Sara McKinnie

PROOF EDITOR

Sue Herms

IWMF is a 501(c)(3) tax exempt non-profit organization Fed ID #54-1784426. Waldenström's macroglobulinemia is coded 273.3 in the International Classification of Diseases (ICD) of the World Health Organization.

PRESIDENT'S CORNER



Judith May, President

In August the IWMF Board of Trustees gathered for its quarterly meeting, which included an extra day for a strategic planning session. Discussion ranged from a review of our vision and mission statements to how to plan for our future. Should we hold the course, continue to grow, or backtrack a bit to find more solid financial ground? Needless to say, it takes more than a day to plan the future and our discussions will continue during the year.

You have a major role to play in the future of the IWMF. An important factor for the future rests, of course, on what the financial support will be for the IWMF. Equally important is your willingness to serve. As you know, we have lost wonderful, dedicated trustees and volunteers recently. It is very necessary that there be members willing to step forward and volunteer to serve on the IWMF Board and to work on various projects.

I would like to point out the IWMF services and the research projects where growth has taken place in the past few years, a growth accompanied by increased expenses.

MEMBER SERVICES

THE TORCH: The *Torch* newsletter contains many more articles and information than ever before and has nearly doubled in size in the past three years. We know this is an important educational arm of our program from the comments we have received and because it was the favored service in the membership survey of last year. In 2007, the average number of pages per issue was 17; in 2008, it was 21; in 2009, it was 30; in 2010, it was 33. As the size of the newsletter has increased, so have printing and postage costs.

PUBLICATIONS: Normally we review and update our booklets every two years, and we have a number of topics in the wings for developing new booklets once we know what our 2012 budget can afford. The demand for IWMF publications has increased and we find that we need to reprint more frequently. This makes for higher printing and postage costs.

INFO-PAKS: These are the large packets of basic information on WM that we send to each new patient who contacts us. I am sure you remember the day you got your INFO-PAK. We updated and streamlined the INFO-PAKS this year and continue sending out between 600-700 annually to new patients who request them. Again, this adds to printing and postage costs.

SUPPORT GROUPS: The number of support groups has continued to grow, and a four-member team led by Trustee Cindy Furst provides assistance with ideas for programs and for a variety of different meeting structures to help the new support group leaders. Cindy's team helps all groups and their leaders to have meaningful meetings. The support group leaders are invited to a training workshop every other year that coincides with the Ed Forum. The IWMF supports the training workshops and they are free for the leaders.

WEBSITE: The new IWMF website was totally renovated and launched one year ago to bring far more educational information to our members. (See page 25 for a review of the first year's outreach) The next stage is to add multi-lingual international pages for our overseas members. We hope to do this within the next year. The renovations and expansions were costly. It is our hope to continue this work and to complete the new website in the course of 2012.

ED FORUM: We have had many requests for topics not covered before, and in the past few years we have expanded our Ed Forums to begin Friday morning and continue until Sunday noon, providing two and a half days of presentations by expert physicians and researchers. This has increased costs. Each year at the chosen location we contract with a hotel, which involves estimating the number of people who will attend and reserving rooms and planning meals for that number. For many years we consistently had 300 attendees. However, in recent years the attendance has slowly dropped while other meetings and seminars for WM patients have appeared. We are working to coordinate timing with other meetings and to encourage attendance at the Ed Forum. The Ed Forum is more informative than ever before, while continuing to provide opportunities for you to speak with physicians, researchers, and other patients.

The **INTERNATIONAL PROGRAM** has drawn more attention in the past few years. As the number of members in any one country grows we assist them in finding each other and in locating a committed person willing to start a support group. The international program is chaired by Trustee Dr. Guy Sherwood who assists and encourages the country support groups to organize and become independent. We also are partnering with the EWMnetwork (European Waldenström's Macroglobulinemia network) based in the Netherlands and expect that jointly we will develop more support groups. You will find an article written by the EWMnetwork secretary on page 14. We have organized and supported two International Patient

President's Corner, cont. on page 4



Forums, in 2008 and 2010 (Stockholm and Venice), and supported patient seminars in the UK. A third International Patient Forum is planned for 11 March, 2012, in London. See page 13 for further information.

RESEARCH PROGRAM

The most excitement since the IWMF began lies in recent advances in research and in our ability as a foundation to support these advances. Did you know that we now have four mice that have been developed carefully and deliberately to have WM? And, if they are confirmed to develop WM-like tumors, more such mice will be bred with the intent of making them available to WM researchers? Likewise we are in the second year of the development of WM cell lines and of another project to gather blood and tissue – all to be used to promote research. In addition, with current discoveries regarding gene therapy and vaccines and the wonderful work being done to understand the genetics of WM, the world of WM research has taken a leap forward. We hope the IWMF will continue to be a major player in that world.

As we enter the last quarter of 2011 you will be seeing more fundraising messages coming to you. This is a normal happening with the many organizations that depend on contributions to stay alive. The IWMF is one of them.

We have been fortunate in the past few years that you found the IWMF important enough to provide the funds to support member services and research. You made it possible for us to continue to grow and thrive. Whether or not we continue on this path will depend on the gifts we receive from all of you. Our potential is great. The funds we receive will determine whether or not we can achieve it.

You have the opportunity to participate in the future of the IWMF with your donation and your willingness to serve.

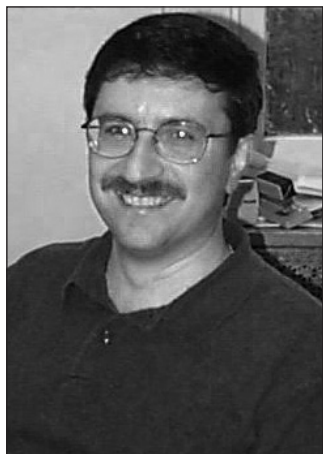
Stay well,

Judith

This President's Corner is dedicated to the memory of Ron Draftz, whose death came so suddenly last month. We are left with memories of the fine qualities of this kind man, of his high intelligence, his great understanding of human nature, and his loving compassion for others. May he rest in peace.

PETER DeNARDIS HONORED BY JEFFERSON AWARD

BY SUE HERMS, IWMF TRUSTEE



*Peter DeNardis, IWMF Trustee,
Webmaster, and IWMF-Talk
Manager.*

The IWMF is very pleased and proud to report that one of our fellow WMers, Peter DeNardis, is the recent recipient of a 2011 Jefferson Award, a prestigious national recognition system honoring community and public service in America.

The Jefferson Awards program was established in 1972 by Jacqueline Kennedy Onassis, U.S. Senator Robert Taft, Jr., and Sam Beard to honor the unsung heroes of our country – our volunteers. The program is

named after founding father and U.S. President Thomas Jefferson. The Jefferson Awards are presented on two levels: national and local. Past recipients on the national level have included Oprah Winfrey, Peyton Manning, Bill

Gates, Condoleezza Rice, Faith Hill, Lance Armstrong, and General Colin Powell.

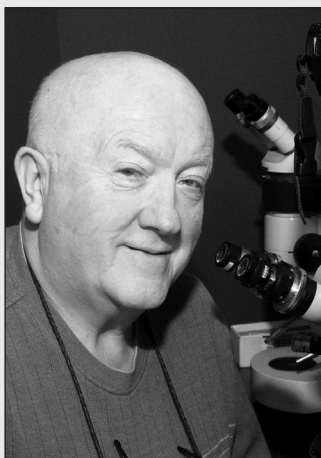
Peter's award is part of the local program, and his is co-sponsored by the *Pittsburgh (PA) Post-Gazette* to honor 50 "community champions" in the Western Pennsylvania area. Each local winner will be highlighted in a newspaper profile and honored at a reception where he or she will receive the bronze Jefferson Award medallion, commissioned by the Franklin Mint. Local leaders then will choose one winner to represent Western Pennsylvania at the national Jefferson Awards ceremonies in 2012 in Washington, D.C., where winners from other local programs across the country will also be recognized.

Peter, who is familiar to many of us, won his award primarily because of his outstanding volunteer commitment to help his fellow WMers through his work with the IWMF. In the past he has also volunteered for Habitat for Humanity of Beaver County, PA, and is very active in his church.

Peter was diagnosed with WM in 2003 and joined the IWMF

Peter DeNardis Honored, cont. on page 13





Ronald G. Draftz

1937-2011

It is with great sadness that I wish to relay to you the recent passing of an IWMF member who has touched the lives of many of our members in an extraordinary manner.

On Saturday, August 20, 2011, Ronald (Ron) G. Draftz passed away from complications due to WM at his home in Arlington Heights, Illinois (USA), while surrounded by his family.

Ron was a research scientist at the Illinois Institute of Technology, a caring father and husband, and a doting grandfather. He enjoyed taking photos of family, friends, weddings, and celebrations. He also went after the big freshwater muskies while fishing with his son, Dave.

When first diagnosed in 2001, Ron applied his keen intellect and scientific background toward understanding the mechanism of Waldenstrom's macroglobulinemia at a level parallel to that of our most learned WM researchers. Since that time he has been a tireless friend of the Foundation and of all those affected by the disease, always giving freely of his time and inexhaustible knowledge and guiding many WM patients in distress through the trials and tribulations of diagnosis, prognosis, and treatment.

Ron spent time on the IWMF Board of Trustees, worked on many IWMF initiatives, was until recently a dedicated member of our Research Committee, revived a Patient Database project, founded the quirky 10K club, spearheaded the "Doctor on Call" *Torch* articles, served as "backup" moderator for IWMF-Talk, was a prolific and valued IWMF-Talk contributor, was co-support group leader for the Chicago area, was for years the official Ed Forum photographer, and much more. He will be remembered by many for his humor and his in-depth knowledge of our disease and the science behind it.

Ron had been battling serious complications due to WM for several months – complications which caused an unusually high level of IgG (yes, "G"), and consistently dropping WBC and hemoglobin, requiring frequent transfusions. He recently had difficulty keeping down sufficient quantities of food and became weak. Just two months ago, Ron was at the Educational Forum and seemed his normal bubbly self, even opening up his room to host the 10K club and anyone else who wanted to join a vibrant cocktail reception. We were truly graced again by his presence and his ready smile at the Ed Forum for what was to be the last time.

It's our understanding that Ron was of the Catholic faith . . . if there is an embodiment of what it is to be a Catholic saint in these modern times, Ron is just that. He gave freely of his time and his intellect to console, comfort, and guide others. Through his strength, grace, and humor, Ron was able to display to us what it means to truly live.

As with the passing of other noted IWMF members before him, the "torch" has now been passed to the rest of us to follow his example – to provide comfort and support to others, to work tirelessly towards a cure for WM, and to live life to the fullest.

Please remember Ron's family – his wife Germaine, daughters Angelique and Aimée, son David, his seven grandchildren (whom he cherished dearly), and the rest of his family in your thoughts and prayers. It should be noted that his family had also graciously suggested that those wishing to celebrate Ron's life and his contribution to others could do so by making donations to the IWMF. We thank them for that and, more importantly, for their having allowed us to be graced by Ron's presence and caring touch.

This remembrance of Ron Draftz was written for the Torch by IWMF Trustee Peter DeNardis. Ron Draftz was Science Advisor for the Torch, and the Torch team's loss with his passing is both personal and collegial. We share the sentiments so aptly expressed by Peter.



RESEARCH UPDATE

RESEARCH FUNDED by the IWMF

BY TOM MYERS, IWMF VICE PRESIDENT FOR RESEARCH

Exciting results have been achieved by IWMF-supported researchers in the last two years. In 2008 scientists from around the world met to develop a program that would have promise in understanding the disease Waldenstrom's macroglobulinemia (WM). Their recommendations were to develop cell lines representative of the disease, breed mice that would acquire WM, and provide a tissue bank of WM cells available for all scientists. These "tools" would allow researchers to study the disease and its treatments without using human patients. Four researchers were funded by IWMF and LLS to develop cell lines for different types of WM. After one year at least two cell lines have been successfully produced by Dr. Ansell of Mayo and Dr. Chanan Kahn of Roswell Park Cancer Institute. The projects were funded for an additional year with the expectation that additional cell lines will be developed by Dr. Ghobrial of Dana-Farber Cancer Institute and Dr. Suning Chen of Soochow Hospital in China. The new cell lines will be available for all WM researchers.

The mouse development under the direction of Dr. Siegfried Janz of the University of Iowa has proceeded exceptionally well. Dr. Janz reports that he has produced mice which develop tumors like WM at a fast rate. Further work is required to develop a mouse strain that produces only IgM from the tumor cells.

The development of the tissue bank by Dr. Ghobrial has proceeded slowly because of the difficulty in acquiring samples. Dr. Ghobrial has suggested some new approaches to the problem that are being reviewed by the IWMF Research Committee. IWMF members could help this program by contacting Dr. Ghobrial and offering to participate in the program.

Dr. Ansell has made good progress in identifying the proteins that contribute to the growth and death of WM cancer cells.

Finally, Dr. Treon of Dana-Farber has completed the first whole genome sequencing of the genes from WM patients. This project has identified a gene which appears to be specific to WM patients. This is a major breakthrough in research and could lead to the development of new treatments for the disease.

At the recent IWMF Educational Forum on WM held in Minneapolis, Dr. Janz, Dr. Ansell, and Dr. Treon presented the latest and very encouraging results from their research projects.

Summaries of these three presentations are now available in the *Ed Forum Review: 2011*, a separate IWMF publication mailed to you together with this issue of the *Torch*. In addition, the three lectures were recorded at the Forum and are included in the set of DVDs from the 2011 Ed Forum. To purchase the 3-disc DVD set, please use the form on the back cover of the enclosed *Ed Forum Review: 2011* or visit us online at www.iwmf.com

RESEARCH FUNDED by the WMFC

For the past 18 months Dr. Brad Nelson of the British Columbia Cancer Agency has been busy researching "The Immune Response to WM: Implications for Immunotherapy" at the Deeley Research Centre in Victoria, BC, Canada. Dr. Nelson's research proposal was approved for funding by the IWMF Research Committee; however the grant, which is for two years beginning January 2010, is wholly funded by WMFC, the Waldenstrom's Macroglobulinemia Foundation of Canada (the Canadian chapter of the IWMF).

Recently we have heard much in the news about the manipulation of the immune system in the fight against lymphomas. IWMF members can be justly proud of their support of this timely and groundbreaking research. Below, Dr. Nelson provides a layperson's summary on the current progress of his research.

Guy Sherwood, M.D., IWMF Trustee

THE IMMUNE RESPONSE TO WM: IMPLICATIONS FOR IMMUNOTHERAPY

BY BRAD NELSON, PH.D.

As we are all aware, the immune system is responsible for fighting infections, such as influenza and the common cold. Interestingly, recent studies have also demonstrated that the immune system can help control cancer progression and can even eliminate tumors. Certain white blood cells, called T-cells, are particularly important for this anti-tumor immune response. Cancer patients with good anti-tumor T-cell responses generally have a better prognosis than those without. Dr. Brad Nelson's goal is to use therapeutic vaccination to enhance the anti-tumor T-cell response in patients with Waldenstrom's macroglobulinemia and other lymphoid cancers. In order to do this, he needs to identify vaccine targets that are unique to cancer. One such target is the tumor idiotype, which has already been targeted in numerous vaccine trials for various types of lymphoma and myeloma. Moving forward, vaccines will likely be most effective when multiple aspects of the tumor are targeted simultaneously. Thus, Dr. Nelson's team is currently working to identify new targets for WM.

Cancer is caused by mistakes in the genetic code that endow cells with abnormal growth properties. Some cancer cells have hundreds or even thousands of mutations, but recent advances in genomic sequencing technologies make it possible to find all of these mistakes in an individual's tumor. The challenge now is to develop new treatments that target these tumor mutations. Importantly, some of these mutations can be detected by T-cells. Dr. Nelson's team is therefore using this approach to identify new vaccine targets for WM. They will then determine which mutations are recognized by T-cells and use this information to design future immunotherapy trials.



THE 2011 IWMF MATCHING GIFT PROGRAM

By now, you've probably heard that some generous WMers have pledged to match up to \$50,000 in new gifts to Member Services so that the IWMF can receive \$2.00 for every \$1.00 you give. Here's how the matching program works:

- If you are a new member, your entire gift will be matched.
- If you've been a member and you increase your 2011 gift to the Member Services Fund over what you gave last year, the increase will be matched.
 - For example, if you gave \$200 to Member Services in 2010 and you now give \$300 total in 2011, the extra \$100 will be matched and the IWMF will receive a total of \$400.
- If you make a 3 year commitment to the Member Services Fund, your gift for the **first year** will be matched.
 - For example, if you've been donating \$200 a year and now commit to giving \$200 a year for the next 3 years, the IWMF will receive matching funds and your 2011 gift will grow to \$400.

If you can't make an extra gift now, suggest that your family and friends make a gift in your honor or in memory of someone else. Send them to <https://www.iwmf.com/donate/donate.aspx> and ask them to select "in honor of" or "in



The IWMF Fundraising Team – Carl Harrington (left) and Don Brown (right).

memory of" under the Make a Gift section. The amount they give will be matched. With the holiday gift giving season coming soon, keep this idea in mind instead of a material gift.

Your generosity will help the IWMF Member Services Fund stay strong and expand services such as:

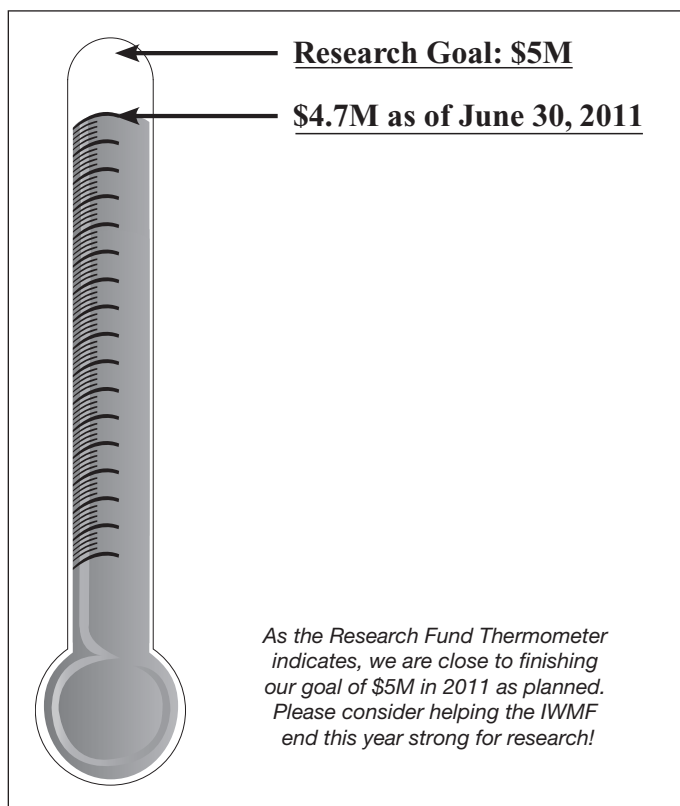
- Increasing awareness of the IWMF by reaching out to new patients with our information and bringing new members into the IWMF family;
- Translating our materials into Spanish and other key languages so others can have access to our materials in their native language;
- More frequent updating and expansion of our publications;
- Improving and adding to our Support Groups;
- Completing our Patient Database.

Make your commitment today. The first \$50,000 in qualifying Member Services gifts will be matched.

To make it even easier, you can cut out or copy the form on page 8 and send your completed form to Julie Jakicic at IWMF Business Office, 3932D Swift Road, Sarasota, FL 34321-6541.

All Canadian donations should be sent to Arlene Hinchcliffe at Waldenstrom's Macroglobulinemia Foundation of Canada to participate in the IWMF matching gift program. Mail Canadian donations to:

Arlene Hinchcliffe –WMFC
260 Dalewood Drive,
Oakville, Ontario L6J 4P3
Canada



2011 MATCHING GIFT PROGRAM

Name _____

Street _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Amount \$ _____ ☐ Check is enclosed

Credit Card Number _____

Expiration Date _____ Signature _____

This is a Multi-Year Pledge ☐ monthly ☐ quarterly ☐ annually of \$ _____ continuing for the next _____ years for a total gift of \$ _____. If your gift is annual, choose the month when we should remind you about your pledge. (_____ month)

.....
This is in Honor of _____

Please send an acknowledgment letter to _____

Street _____

City _____ State _____ Zip _____

.....
This is in Memory of _____

Please send an acknowledgment letter to _____

Street _____

City _____ State _____ Zip _____

THE MINNEAPOLIS ED FORUM

BY SECRET WALLIE

He's back! Secret Wallie, our incognito correspondent who last reported from Memphis, returned this June to the Educational Forum in Minneapolis and provided a running account of events sent to IWMF-Talk for the benefit of those who could not attend. In the excerpts below, Secret Wallie shares his patient's perspective of this year's Ed Forum.

[Note: coverage of detailed scientific and medical information is not included in Secret Wallie's report. The scientific and medical presentations were videotaped and are available in DVD format; summaries of these presentations are published by the IWMF in the Ed Forum Review: 2011. See below for details.]

Thursday, June 23

'Tis the eve of the 2011 Ed Forum – the official festivities begin tomorrow, but the Mayo Clinic tour, a special feature

of this year's Forum, is this afternoon. Upon arrival at the hotel, one could notice the early bird WMers arriving and sense their anticipation and excitement. The hour-and-a-half bus ride to Rochester, Minnesota, was enjoyable, with tasty box lunches provided to all attendees and much lively conversation between fellow riders.

The Mayo Clinic tour itself surpassed expectation. I soon came to realize that it's more than just a "clinic" – it's a true campus or city in and of itself. We were first ushered into an auditorium to view a short documentary on the history of Mayo Clinic, and then Dr. Robert Kyle turned oral historian and recounted the history of Mayo as he walked us through various historical exhibits. Dr. Morie Gertz next led us on a tour of the amazing collection of artwork that adorns the walls and halls

The Minneapolis Ed Forum, cont. on page 9



of the Clinic – all pieces donated by patients in honor of their doctors. The collection includes various paintings, drawings, and sculpture by well known artists (Andy Warhol, Chihuly, and the like). Dr. Gertz shared his interesting perspectives on the artistic merits of each piece and revealed an amazing talent for spotting and appreciating great art. We understood that Mayo Clinic does take great pains to ensure that its walls and open spaces are designed to give one a feeling of warmth, of comfort, and of wonder – to take your mind off the fact that you're there for medical reasons.

Dr. Stephen Ansell led the clinical tour and guided us through the infusion rooms, the pheresis units, the patient care areas, and various other sections of the clinical side of the hematology department. He noted that the hospital is directly connected to the hematology treatment area – making it very convenient and easy for patients and physicians to go between the two for treatment and consultation. On the fourth and final portion of the tour, Dr. Anne Novak and Dr. Lucy Hodge led us through the research area of the hematology department. We were taken through the various blood analysis and research labs, we saw first hand the equipment for flow cytometry and many other devices used to analyze our blood and to do research. The doctors informed us about the research mission of Mayo Clinic: to foster collaboration so that critical knowledge is shared among the researchers working side by side on all types of blood cancers!

The Mayo tour was an impressive display of what makes a research center great – the facilities and the outstanding doctors and staff inspired by a determination to advance the leading edge of medical science. We are so fortunate that our orphan disease has found itself a spot at this edge! And we warmly thank Drs. Ansell, Kyle, and Gertz and also their colleagues for doing so much on our behalf. Including the opportunity to visit them in Rochester!

Rumor has it that, back at the hotel, a “10-K soirée” was hosted in the evening by Ron Draftz. It was an informal reception for those who have reached the “magic number” of 10,000 mg/dL of IgM, and Ron provided a great selection of fine wines. (Pete DeNardis even brought a couple of bottles of his homemade wines.) The soirée and other impromptu events serve as an important reminder that attendees are not there just to learn about manifestations of and treatments for WM but also to support each other in this rare journey we are all traveling on.

Friday, June 24

On Friday morning the Early Bird Sessions introduced topics basic to the understanding of WM. In quick succession we covered plasmapheresis (Dr. Jeff Winters), complementary and alternative medicines (Dr. Guy Sherwood), bone marrow biopsy procedures (Dr. William Morice), and peripheral neuropathy (Dr. Michelle Mauermann). After a brief visit to the sandwich buffet we were back to hear Dr. Stephanie Gregory discuss new and emerging treatment options and to learn from Dr. Siegfried Janz about the WM mouse model he is developing as the recipient of a IWMF research grant.

Break out sessions followed mid-afternoon and included sessions for caregivers, the newly diagnosed, treatment veterans, and those interested in estate planning and pain management. Attendees gravitated to the topic that was of particular interest to them and met in informal meeting room settings to discuss the topics moderated by IWMF trustees and fellow patients.

Throughout this busy and full day one encountered folks lined up in front of each speaker after each session; and the doctors also came to the lunch and dinner and graciously gave of their time to speak to patients about their conditions and offer advice and insight. On many occasions, one could actually see the fear that was evident in many of the first timers' faces just melt away as they spoke with the doctors and researchers. That in itself is well worth the cost and time it takes to attend an Ed Forum! Such help and comfort one just can't put a price tag on!



Forum physicians participate in the social events and are available to converse with patients and caregivers and respond to their concerns. Here Dr. Gertz (center) joins Forum attendees for lunch.

Did I already mention dinner? Friday evening was the social highlight of the Ed Forum with the Welcome Dinner preceded by the President's Reception. IWMF President Judith May warmly welcomed everyone and was pleased to note that many of the presentations at this year's events were a direct result of IWMF-funded research. Michelle Blazek, the Minneapolis support group leader, was introduced as the “mayor of Minneapolis” and presented an entertaining speech with some interesting facts about Minneapolis and Minnesota during dinner. Michelle and her husband, Scott, were, in a sense, volunteer ambassadors for Minneapolis during the Forum. Many thanks to both of them for helping to make all of us feel so welcome!

The keynote speaker of the evening, Mark Schaible, was an Air Force test pilot scheduled to go on a space shuttle mission until he was diagnosed with WM. Several years ago Mark underwent an allogeneic transplant following unsuccessful chemo attempts. The result: he was cured. Since his diagnosis and cure he has chosen to pass along to others the motto “Thrive and Not Just Survive.” Recently he attempted





The friendly atmosphere at the Ed Forums encourages patients and doctors to “rub shoulders”. Here Jack Whelan, our IWMF volunteer photographer, and Dr. Robert Kyle.

to scale Mount Everest as part of an expedition crew and almost completed the climb. Mark’s message was uplifting and motivational. He encouraged everyone to consider a diagnosis to be an opportunity to truly live.

Saturday, June 25

The day began bright and early, with some doing yoga at 6:30 am, and the first session starting at 8:00 am! There was also a plentiful breakfast for all, with researchers, presenters, and patients gathered around at tables breaking bread, or perhaps eggs, and discussing medical issues, sharing life stories, or just telling a joke or two.

The Saturday morning session began with double tracks. For newly diagnosed patients Dr. Kyle spoke on understanding lab test results and was followed by Karen Lee Sobol who recounted her experience as a WM patient and how she achieved a cure. Karen Lee, by the way, is the author of a book entitled *Twelve Weeks* (to be published soon) that expands further on her successful quest for a cure. The second track was directed to WM veterans and offered a patient panel (comprised of Bill Bass, Ron Draftz, and Pete DeNardis) where each “veteran” presented different manifestations of WM and different disease progression. Each faced significant challenges and yet each had passed the mystical “median life expectancy of 7 years.” Dr. Rafat Abonour addressed the veterans next and did a fantastic job of delineating the difference between autologous stem cell transplants and allogeneic stem cell transplants for WM. A quick break for snacks and chat concluded the double track programming.

Back to the program and the spotlight was on the Mayo Clinic team of seven researchers led by Dr. Stephen Ansell.

Dr. Ansell outlined the many very promising research projects directed at WM that are currently underway in the hematology laboratories. Dr. Anne Novak reported the exciting news of the WM cell line successfully developed at Mayo, and Dr. Lucy Hodge Hodge explained how drugs blocking the JAK/STAT signaling path may control WM (both doctors were familiar to those of us who spent Thursday afternoon touring Mayo Clinic).



Members of the Mayo Clinic team. From left to right: Dr. Lucy Hodge, Dr. Anne Novak, and Dr. Stephen Ansell.

Dr. Esteban Braggio discussed on-going genetic studies in his laboratory pointing to overlap in gene abnormalities between WM and other B-cell lymphomas, and Dr. Francis Baudi shared his insights on the epidemiology of WM, citing statistics of interest to all of us (for example, median disease-specific survival is now bumped up to 10 years). Nephrologist Dr. Nelson Leung had lots of very specific information about WM and kidney issues – are you aware that kidney disease occurs in many other diseases which have monoclonal gammopathies? Clinical trials in WM were covered by Dr. Craig Reeder who led us from a general discussion of why patient participation in clinical trials is so important to outlining the classes of drugs now being tested. Dr. Reeder listed five trials currently underway for WM at Mayo Clinic. It remained for Dr. Morie Gertz to conclude this session with remarks about the Clinic’s extremely strong research program and the integrated care Mayo provides, enabled by electronic records so that doctors in all three centers (Rochester, Phoenix, and Jacksonville) collaborate on patient care.

What a morning! Heads spinning, we made our way to a delicious luncheon that restored us for the afternoon ahead. This might be a good spot to remind you that the presenters

The Minneapolis Ed Forum, cont. on page 11

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@sy-thetis.org



from this morning's energetic program (and those from Saturday afternoon and Sunday morning, too) are "alive and waiting" for you on the Forum DVDs. And don't forget that summaries of the talks are to be found in the *Ed Forum Review: 2011*.

Speakers on Saturday afternoon reported on several cutting edge research programs. Dr. Larry Kwak led off with a discussion of the progress towards vaccines for lymphoma – the theory involved, the progress so far, and encouragement to see the newer, improved DNA fusion vaccines leading to such a vaccine for WM. We next heard Dr. Aldo Roccaro's review of several studies on three new drugs targeting the P13K/Akt/mTOR pathway. The third speaker, Dr. Fred Hochberg, approached a subject that is new to the IWMF Ed Forum: a discussion of Bing-Neel Syndrome, or WM affecting the central nervous system. Stressing the rarity of BNS, Dr. Hochberg spoke of symptoms, diagnosis, and therapy, together with a call for further study. Dr. Ansell was back at the podium, this time to discuss his own research (funded by IWMF dollars) on cytokines in WM and how manipulating three of them (BLyS, IL-6, and CCL5) has the potential to control IgM levels in Wallies like us. The session concluded with Dr. Kyle who carefully explained how MGUS and smoldering WM differ and their risks of progression to "full blown" WM.

There were no "official events" following this long day so full of information, impressions, and personal contacts. Many Forum attendees convened with newly found friends for dinner at local restaurants (there were many available in downtown Minneapolis, within walking distance of our hotel).

Sunday, June 26

Another bright and early start to the day with yoga at 6:30 am, breakfast at 7:00 am, and the first presentation at 8:30 am. Yet, there they were, patients and doctors early on a Sunday morning gathered in the breakfast area, eating together and discussing various issues regarding WM and even just life in general.

Last, but definitely not least, was Dr. Steven Treon, presenting us all with very exciting news! With the support of the IWMF, he has continued his familial genomics project and can now delineate some differences in response to therapy between those patients with familial WM status versus those with sporadic status. Dr. Treon outlined a range of treatment options based on new research on rituximab, immunomodulatory drugs, proteasome inhibitors, bendamustine, GA101, and RAD001. And here's the really exciting part. We will be hearing more soon about the latest from the whole genome sequencing project in WM. The Bing Lab has located a single gene that is unique to WM and is found in the WM cells of 90% of the patients studied. The gene is not found in IgM-MGUS or in myeloma. More information will soon be published in a professional journal – but we heard it first from Dr. Treon himself at the IWMF Forum!

At the "Ask the Doctor" session – one of the highlights of every Ed Forum – Dr. Kyle moderated the panel comprised of Drs. Fred Hochberg, Steven Treon, Rafat Abonour, and Morie

Gertz. Quite a collection of brainpower and WM expertise all on one stage, to say the least!



Dr. Steve Treon (left) and Dr. Rafat Abonour (right) enjoy a moment of levity during the "Ask the Doctor" session on Sunday. The informal atmosphere where expert knowledge combines with good humor makes the "Ask the Doctor" a very popular event.

As usual, Dr. Kyle was a great moderator as he kept the flow of questions and responses going while he shuffled through the index cards of questions submitted by WM patients and caregivers at the Ed Forum. Dr. Kyle was careful to select questions that would be most applicable to everyone in the audience. If you want to hear the questions and the lively response from the experts, you'll just have to visit the Forum DVDs!

The last item on the agenda for Educational Forum 2011 was the IWMF Business Meeting, where the Board of Trustees presented a summary of the past year's activities from the various committees: Support Groups, International, Website, Fundraising, Publications, Research, Scientific Advisory, and Financial. IWMF members have this opportunity each year to ask questions of the Board members. Several members took this opportunity and Board members did their best to provide clear and concise answers. And with this the 2011 Forum was concluded.

Another wonderful opportunity to learn so much about all that's happening in the world of Waldenstrom! Before Secret Wallie bids everyone adieu for this year, I'd like to reflect for a moment on some things that occur at Ed Forums that are not part of the regular program, including:

- Patients from different parts of the world form new friendships and bonds that can last a lifetime. Fellow patients and caregivers came from different parts of the US and from other countries also. There were attendees from Canada, Israel, Finland, and Australia – all speaking the same language of comfort, hope, and healing!
- After each session, patients line up to speak one-on-one with the presenters, to ask personal



medical questions – and the doctors patiently give of their valuable time to answer each question and help the patients. This never ceases to amaze me!

- Support for those who feel troubled by their condition is always available; the researchers are always willing to give caring consultation and suggestions to those who need it.
- Many different publications and pamphlets are available at the registration desk for all attendees.
- A 45-minute time slot for each presentation enables the presenters to explain their topic in layman's terms so that those of us who are not scientifically-minded can grasp the scope of their message.
- It's a time of celebration for patients and caregivers – to celebrate being together and surviving and thriving for another year.



Caregivers were presented with a red carnation in honor of 2011 being designated the "Year of the Caregiver." It's a small token of appreciation and only scratched the surface of the amount of gratitude and respect we patients have for our caregivers!

- Getting to know what makes the IWMF tick – why it exists and what it does. The fact that everyone engaged is a volunteer is important to notice, and it is quite unique among cancer foundations! We should all consider volunteering in whatever way we can.
- One does not go hungry at an Ed Forum . . . the lunches, breakfasts, and dinners were fantastic, as were the food and drink items available during the morning and afternoon breaks; in a sense, quite a nurturing environment!
- A LOT of things happen behind the scenes to make this truly a fantastic event – the Ed Forum Committee and the IWMF staff (especially our office manager Sara McKinnie) make every effort to ensure that the Forum runs smoothly.



Dr. Stephanie Gregory (right) receives a copy of Twelve Weeks from author Karen Lee Sobol.

- Smiles, laughter, gentle support are the order of the day.
- No one, and I mean NO ONE, looks sick! It's quite difficult to discern who is the patient and who is the caregiver.
- Researchers and presenters also become audience members as it is an opportunity for them to learn about various aspects of WM research that is occurring around the world.

Did I mention that the presentations from WM patients who have survived and are relatively cancer-free (if not cured) were an inspiration to all of us? Stories from Karen Lee Sobol, the author of *Twelve Weeks*, and Mark Schaible, the keynote speaker and fighter jet test pilot and Mt. Everest climber, were proof positive that many of us can beat this disease!

The last day comes much too quickly. You're just starting to get a handle on the science and biology of the disease – just starting to glimpse the intricacy of our immune system – and then the sessions are over! The bonds you are forming with fellow patients and caregivers are strengthening, only to find you have to depart from each other and may not see each other again for another year or two, or ever. Sure, there is the Internet, but it's not quite the same as the physical connection that is formed at the Ed Forum. It's like attending a family reunion in many respects, but with family members that you actually like!

I'll be looking for YOU next year!

Secret Wallie (or maybe Secret Waldie – a new term I heard spoken by someone – at least, it's new to me!)

The Ed Forum Review: 2011, mailed to you with this issue of the Torch and online at www.iwmf.com, contains summaries of the presentations referred to by Secret Wallie.

The sessions of the 2011 Ed Forum were taped and are now available in DVD format. The DVDs include slides shown at the Forum. How to order? Please use the form on the back cover of the enclosed Ed Forum Review: 2011 or purchase online at www.iwmf.com



3rd International Patient Forum on Waldenström's Macroglobulinemia

Bringing Doctors and Patients closer in London 2012

Jointly hosted and generously supported by:



**Royal Society of Medicine, 1, Wimpole Street, London W1G 0AE
Sunday 11 March 2012**

**Keynote Speaker: Dr. Steven P. Treon, M.D., M.A., Ph.D.
Dana-Farber Cancer Institute, Boston, Massachusetts**

We aim to build on the success of Stockholm and Venice Patient Forums and the January 2011 WMUK seminar which had 120+ attendees. With your support, we anticipate this will be the biggest and most exciting doctor-patient WM meeting ever held outside the USA. It's a cost-effective, packed one-day conference where international WM specialists present at an understandable level and meet patients to discuss latest treatments.

Sessions planned so far include Bone Marrow Transplant, Neuropathy, Novel Drugs, Intro to WM, Patient View, and 'Ask the Doctors' session. Interactive audience voting. WM 'patient tales' wall. Optional Saturday Tour of London 2012 Olympic Site. Discounted nearby Central Hotel Accommodation. Make a long weekend of it! Fee includes working lunch + refreshments. Medical professionals' Dinner and WMUK Award Ceremony on Saturday.

To receive advance information, e-mail: info@wmuk.org.uk

Cost per delegate £35/€40/us\$55.

Online registration in most currencies will be available from 20 September at www.wmuk.org.uk

Peter DeNardis Honored, cont. from page 4

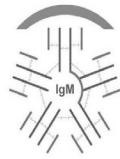
Board of Trustees in 2008. In that capacity, he serves on the Publications Committee, was instrumental in helping to set up our new and improved website, and is currently our website administrator. He also is an important member of the Patient Database Team, developing questions for our WM patient database and coordinating the process of converting these questions to a format appropriate for computer use. Many of us probably know Peter best as the manager of our popular IWMF-Talk, an e-mail discussion list where all matters regarding WM are discussed among patients and caregivers.

Peter and his wife, Terri, live in Aliquippa, PA, and have three children, Anthony J. (Joey), Nicole Antonia, and Ryan. Peter graduated from Robert Morris University in 1983 and received an MBA in Information Systems from the University of Pittsburgh in 1989. He is an Information Manager for the University of Pittsburgh.

In his spare (?) time, Peter and his cousin enjoy making wine together. They buy crates of red and white grapes and do all the processing to produce bottles of Merlot, Chardonnay, Chablis, Pinot Noir, and other varieties. In the winter months, Peter makes prosciutto and dried sausage. He also loves to read, play tennis, walk, ride his bike, and travel. As you may have guessed by his interest in wine and prosciutto, Peter's heritage is Italian, and Italy is one of his favorite places to visit – he enjoys everything Italian and has taught his children about his Italian traditions.

A well-deserved tip of the hat goes to one who wears many hats for the IWMF – our own Peter DeNardis!





WHAT IS THE EUROPEAN WM NETWORK?

BY MARLIES OOM, EWMN SECRETARY-TREASURER

The EWMnetwork is a non-profit organisation established in 2009 with a board of European patients and caregivers to represent WM patients at the EU level. Membership is currently open to both support groups and individuals in countries where no support group currently exists. EWMnetwork has a medical advisory board drawn from 8 countries and is financed by contributions from countries where patient advocacy is funded nationally, principally the Netherlands. Its operating language is English and its motto is: *Patients for Patients*. More details can be found at www.EWMnetwork.eu or www.waldenstrom.eu. These websites act as contact points for other sources of WM information. We also publish a newsletter.

We are **an umbrella group** for patient support groups throughout Europe **promoting WM patient interests at a European level**, where health care is strongly influenced by European legislation and federal EU bodies. We have, mainly in co-operation with other rare cancer organizations, contacts with EU directors, commissioners and members of the European Parliament, and with other European organisations. We promote patient **interests with other European organizations** such as the European Cancer Patient Coalition, the European Organisation for Rare Diseases (EUORDIS) and the European Medicines Agency. We also attend meetings relating to associated diseases such as myeloma and lymphoma to promote interest in WM, including distribution of our literature.

Another strand is the promotion of **patient trials** for novel medicines and increasing participation in them, as well as trying to give patients a voice in the clinical trial protocols – making trials understandable and practical for patients. We also promote **the availability of new medicines and treatments** and get orphan drug status or treatment approval for WM patients in all European countries.

We want to **develop a closer partnership working with the IWMMF** as our aims are totally complementary. For instance the lack of functioning support groups in Europe is of

concern to both of us. Together we must try to encourage **the development of more support groups within the European Countries**. Of the 29 European Countries (27 EU + Norway, and Switzerland) only 8 support groups (UK, France, Germany, Greece, Netherlands, Belgium, Ireland, Finland) operate in any formal sense. Countries such as Sweden have internationally famous WM expertise but no support groups. Development of support groups could be driven through jointly promoting national and regional meetings and online through both our websites. This hopefully will boost IWMMF membership, which is low in these countries.

EWMnetwork and IWMMF board members meet informally on many occasions. Board Member Veikko Hoikkala from Finland went as our representative to the Ed Forum in Minneapolis to advance this partnership and was very encouraged by the forward thinking of the IWMMF Board and with Dr. Guy Sherwood's enthusiasm. We are now working to turn some of the suggestions raised there into reality, such as regular European features in the *Torch*.

Despite limited resources, EWMnetwork is also working to try to increase the amount of information available in **other European languages**. EUORDIS has invited us to participate in a multi-lingual online forum for WM (German, Spanish, English, French, Italian) – see the example at www.rarediseasecommunities.org. This European online WM community may help promote more support groups.

Finally, we are committed to **promoting European WM patient meetings**. Although the EWMnetwork has very limited resources, it has the ability to contribute to such meetings and help with publicity, giving meetings a more European or international 'feel' and encouraging participation of European members from target countries. To this end we, together with the IWMMF and WMUK, are financially supporting the Third International Patient Forum (following on those held in Stockholm and Venice) on Sunday 11 March 2012 at the Royal School of Medicine in London. We hope this will be one of the largest WM patient forums ever.



AN ED FORUM ALBUM: MINNEAPOLIS 2011



Photos courtesy of Jack Whelan

MEDICAL NEWS ROUNDUP

BY SUE HERMS

Phase I Trial Combines Bortezomib and Alvocidib – A Phase I clinical trial of bortezomib and alvocidib (flavopiridol), a cyclin-dependent kinase inhibitor, evaluated dose-limiting toxicities and maximum tolerated dose in patients with multiple myeloma, indolent lymphoma, and mantle cell lymphoma. In this study, 16 patients were treated. The maximum tolerated dose was established as 1.3 mg/m² for bortezomib and 30 mg/m² for alvocidib. Common toxicities included low white blood cell counts as well as fatigue, febrile neutropenia, and elevated AST (aspartate aminotransferase) levels. Two complete responses and five partial responses were observed for an overall response rate of 44%.

Millenium Pharmaceuticals Investigates Subcutaneous Bortezomib – Millenium Pharmaceuticals investigated subcutaneous administration of bortezomib in two clinical trials in multiple myeloma patients. One trial, a Phase III study, involved 222 patients: one cohort received bortezomib as an IV push and the second received it by injection into the abdomen and thighs. The dosage was 1.3 mg/m² for both groups. Similar efficacy was seen between the groups, but the incidence of peripheral neuropathy was less in patients receiving subcutaneous injections: 38% vs. 53% receiving IV infusion. The U.S. Food and Drug Administration has not yet approved subcutaneous administration of bortezomib.

Newer Anti-CD20 Antibody Attains Orphan Drug Designation – AME-133v, a fully humanized anti-CD20 monoclonal antibody, has been granted orphan drug designation for the treatment of follicular lymphoma. A Phase I/II clinical trial with AME-133v for 67 patients with previously treated follicular lymphoma established a recommended dose of 375 mg/m². AME-133v has been engineered for better affinity to the CD20 receptor on B-cells and increased antibody-dependent cell-mediated cytotoxicity (ADCC), which may lead to more effective killing of targeted B-cells.

Study Reports Stem Cell Transplantation for WM – The Blood and Marrow Transplant Program at the University of Minnesota Medical School released a report on stem cell transplantation for WM. The report concludes that autologous stem cell transplantation should be reserved for chemotherapy-responsive WM patients, particularly for those in whom duration of the first remission is less than two years and in patients with intermediate- or high-risk factors according to the International Prognostic Scoring System for WM (IPSSWM). The study also recommended avoiding autologous transplant in patients with chemo-refractory disease and heavily pre-treated patients with more than three lines of previous therapy. Younger, relatively healthy patients with short remissions, high-risk IPSSWM score and elevated LDH could be considered for autologous transplant with curative intent. Increasing experience with reduced-intensity

allogeneic (mini-allo) stem cell transplant suggests that this type of transplant could be extended to the elderly, those with co-morbidities, and those who have relapsed following autologous transplant. However, allogeneic transplantation should be performed in experienced transplant centers within the context of controlled clinical trials.

Project Investigates WM and Risks of Second Cancers – A joint project by the Cook Children's Health Care System, Dana-Farber Cancer Institute, the University of North Texas Health Science Center, and Cancer Centers of North Carolina-Asheville investigated site-specific relative risks of second primary malignancies among patients with primary WM. Data from population-based registries identified 1,521 patients with primary WM diagnosed between 1973 and 2007. This group yielded 226 second primary malignancies, and higher site-specific relative risks were observed for colon, lung, other non-Hodgkin's lymphoma, myeloma, and acute myeloid leukemia, compared to the general U.S. population. The investigation also stated that the higher relative risks of second primary hematologic malignancies may be treatment-related or immunologically-related, whereas the higher relative risks of second primary solid tumors may be the result of detection bias or risk factors shared between WM and the specific solid tumors.

New Bcl-2 Inhibitor Investigated – The investigational drug navitoclax (ABT-263) has shown significant activity in patients with heavily pre-treated chronic lymphocytic leukemia. In a Phase II study, the drug reached an objective response rate of 33%. Navitoclax inhibits the protein Bcl-2, which regulates apoptosis (programmed cell death).

Japanese Study Detects Chromosome Deletion in WM – The Tokyo Medical University in Japan performed cytogenetic and FISH analyses on nine patients with WM and demonstrated deletions of chromosome 20q in four of nine patients (44%) at diagnosis. Moreover, one patient had appearance of a 20q deletion after chemotherapy, although this patient did not have it at diagnosis. The study concluded that chromosomal breakage at 20q is a non-random genetic change which plays a role in the neoplastic process of WM.

Pixantrone Tested in Combination Therapy in Phase I Trial for NHL – Pixantrone was included in a Phase I study of combination therapy with fludarabine, dexamethasone, and rituximab in 28 patients with relapsed or refractory indolent non-Hodgkin's lymphoma. Pixantrone administered at 120 mg/m² was identified as the recommended dose in this regimen. The overall response rate was 89%, and the main adverse events were low white blood cell counts. Estimated survival was 96% after one year and 92% after three years.

Medical News Roundup, cont. on page 17



Merck Develops Antibodies to APRIL – Merck Research Laboratories and the Academic Medical Center in Amsterdam, The Netherlands, have developed two antibodies to APRIL, which is an important survival factor in several human B-cell malignancies and binds to BCMA and TACI receptors. In mouse studies, these antibodies successfully blocked APRIL binding to CLL-like cells and prevented their survival.

FCR Combination Therapy Reported for WM – The Niguarda Ca' Granda Hospital in Milan, Italy, reported results from a multicenter study of fludarabine, cyclophosphamide, and rituximab (FCR) in 43 WM patients with symptomatic disease who were untreated or previously treated with one line of chemotherapy. Up to six courses were administered, with an overall response rate of 79% and a major response rate of 74.4%, including 11.6% complete responses and 20.9% very good partial responses. The major toxicity reported was grade 3-4 neutropenia. After the end of treatment, 44% of patients had long-lasting episodes of neutropenia, and three patients developed myelodysplastic syndrome.

New Btk Inhibitor in Phase I Trial – Avila Therapeutics is sponsoring a Phase I clinical trial of oral AVL-292 monotherapy in patients with relapsed or refractory B-cell non-Hodgkin's lymphoma, chronic lymphocytic leukemia, or WM. AVL-292 is a highly specific inhibitor of Bruton's tyrosine kinase (Btk), which plays a critical role in the signaling and proliferation of B-cells.

Another Btk Inhibitor to Be Tested in Phase I and II Trials – Another Btk inhibitor, PCI-32765, is being developed by Pharmacyclics, Inc. The company has announced the signing of a five-year Cooperative Research and Development Agreement with the National Cancer Institute to sponsor Phase I and Phase II trials of this drug in various hematological malignancies, including non-Hodgkin's lymphoma and multiple myeloma.

Study Reports Results of Bortezomib, Bendamustine, and Rituximab Combination Therapy – An article in the Journal of Clinical Oncology reported a multicenter study that evaluated the response rate, progression-free survival, and toxicity of the combination of bortezomib, bendamustine, and rituximab in patients with follicular lymphoma whose disease was relapsed or refractory to treatment. The overall response rate was 88% (including 53% complete responses). The median duration of response was 11.7 months, and median progression-free survival was 14.9 months. Toxicities were manageable; myelosuppression was the main toxicity. Transient grade 3-4 neuropathy occurred in 11% of patients.

British Study Elucidates a Mechanism for Rituximab Resistance – Researchers at the University of Southampton

in the United Kingdom have discovered clues about why an estimated 30% of non-Hodgkin's lymphoma patients do not respond to rituximab therapy. They found that in some lymphoma patients, after binding to the CD20 surface antigen of the B-cells, rituximab is quickly internalized inside the cell, meaning that the drug does not work as it should and immune cells cannot seek out and kill the B-cells as effectively. Rituximab is internalized much faster when a molecule called FcγRIIb is also present at high levels, and a small preliminary analysis found that those patients with high levels of this molecule were less likely to be treated successfully. The researchers are now moving forward with a much larger analysis to confirm their findings.

CLL Patients Treated with Genetically Engineered T-Cells – The University of Pennsylvania's Abramson Cancer Center and Perelman School of Medicine have shown sustained remissions of up to a year among a very small pilot trial of advanced chronic lymphocytic leukemia (CLL) patients treated with genetically engineered versions of their own T-cells. The protocol involves removing a patient's T-cells, genetically modifying them using a lentivirus vector, and re-programming them to attack B-cells. The vector encodes an antibody-like protein called a chimeric antigen receptor (CAR), which is expressed on the surface of the T-cells and is designed to bind to the CD19 surface antigen found on normal and cancerous B-cells. When these T-cells are infused into the patient, they focus their killing activity on B-cells. At the same time, a signaling molecule in the CAR also tells the cells to produce cytokines that trigger additional T-cells to multiply, thereby enhancing their killing ability. One patient in this study had a complete response – no evidence of CLL. The team plans to test the same engineered T-cell concept in other CD19 positive tumors.

TRU-016 to Be Combined with Rituximab and Bendamustine in NHL – Emergent BioSolutions has started a Phase I/II study to evaluate TRU-016 in combination with rituximab and bendamustine in patients with relapsed indolent non-Hodgkin's lymphomas. TRU-016 is a CD37-directed small modular immunopharmaceutical. Preclinical studies showed that when TRU-016 and bendamustine were used together, increased anti-tumor activity was shown beyond results achieved when either drug was administered alone.

The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Wanda Huskins, John Paasch, Colin Perrott, Howard Prestwich, and Bert Visheau in disseminating news of interest to the IWMF-Talk community. The author can be contacted at suenchas@bellsouth.net for questions or additional information.



COOKS' HAPPY HOUR

BY PENNI WISNER

When Penni's thoughts drift with the changing season she provides us a memorable lesson in creative cookery. The result: a first-class cooking class act!

Every fall there is a second coming. No, I'm not talking politics, I'm talking fruit. In the cool weather, raspberries appear again in markets and figs bear a second crop. It is the best crop, in my opinion, because the fruit is more intensely ripe. Take advantage of the harvest with the lazy person's preserving method: oven roasting/drying. A technique I rediscover every fall, and so, now you are rediscovering, too. (I am remembering – I can still do that sometimes – that we discussed oven-dried tomatoes last fall.)

The inspiration for oven-dried plums and figs comes from several sources. For one, my friend Peter's parents' richly productive plum trees (and thus a large bag arrived on my doorstep), the flavored prunes you can buy in packages now (talk about a convenient, healthy snack!), and oven-dried tomatoes. Tomatoes, figs, and plums are similar enough in the texture of their flesh and the intensity of their flavors that they can, and do, stand in for each other in many recipes. Secondly, every fall I miss the ranch I lived on, especially for the half-dried figs I'd have to climb a shed roof to pick from the tree. And third – are you still with me? – I had previously done a recipe for red-wine poached figs with rosemary. Rosemary's also great with tomatoes and potatoes (I'm testing your memory here) and so why not with plums?

Oven-dried, spiced plums or figs: What you need – fruit, olive oil, balsamic vinegar, rosemary, cinnamon, allspice. How to use – serve with cheese, with duck, stuff into pork roast, stew with chicken. You could serve them over yogurt and even chop them and stir them into vanilla ice cream to make an unusual sweet-savory dessert. I've also packed the plums into small jars and given them as Christmas gifts. It's not too early to start thinking about the holidays. (Yes it is!)

Take any amount of plums. I particularly like prune plums for their size, texture, ease of pitting, and balanced, complex flavors. Pit the plums and toss them in a bowl with healthy doses of olive oil and balsamic vinegar. Use about one part vinegar to 2 to 3 parts olive oil. Add some fresh rosemary sprigs, ground cinnamon and allspice, and a little salt and freshly ground pepper. Toss well and spread on rimmed baking sheets. Put in a slow oven, maybe 200 to 250°F. Let the plums dry slowly, turning and tossing occasionally, until the plums have lost perhaps half their volume and the liquid in the pan is syrupy. This might take 6 hours or so.

Remember that the plums feel plumper and more moist when warm than they will when they have cooled. So, as you think the plums are getting close to being done, take one out and let it cool to see how it is. You want them to remain soft but for

their flavors to be quite intense. Pack the plums into clean jars, divide the pan juices equally among the containers, and freeze.

Honey-spiced plums (Again, I prefer the prune – also called French – plums with their meaty texture.) and figs: this is what cooking is about. Smack a pot on the stove and turn on the heat. Throw ingredients in and get ready to be surprised. It may not turn out just as you thought. But it will be interesting and that means fun.

Here's what I mean: For some reason, when I saw the purple plums bloomed with gray, my first thought was thyme. And so I bought several pounds of fruit, imagining soft, whole poached plums. (In which case, I should have halved, pitted, and oven roasted them. See above.) I put a half cup or so of honey in a large, heavy pot and added what looked like an equal amount – but was probably twice that much – water and put it over medium heat. I opened the cupboard and found vanilla beans stripped of their seeds but the pods were fragrant. They went in the pot with a Turkish bay leaf, many small sprigs of lemon thyme, a few whole coriander seeds, and three whole star anise (one of my favorite spices), as well as a pinch of salt. All that simmered together for about five minutes to meld the flavors. Then I added the three pounds of whole plums and covered the pot. Within 3 minutes, several fruits had split and begun to disintegrate along with my fantasy. Maybe I was making jam.

Then I had the idea of lemon and orange zest and added the grated zest of one-half orange and one lemon plus the juice of the lemon, stirred, recovered the pot, and simmered another fifteen minutes. By then, I had mostly a puree but what a scent! Heavenly vanilla, tart, tangy, sweet. In short, fantastic.

When cool, I fingered through the mass to remove pits and thyme twigs. It would have been faster to halve and pit the plums first. Sometimes being lazy, and not thinking ahead, is not so wise. And if you use figs, this would not even be an issue. Finally, I put the cooked plums through a food mill and found the remaining pits and star anise. If you do this, taste your puree and adjust the flavors to your palate with more honey or more lemon juice. Divide into containers and freeze.

Make use of your honey-spiced plums: As an add-in for yogurt at breakfast and a sauce for rice pudding, tapioca, or custard and ice cream at dinner, to serve with cheese, add to a braise of duck legs (I did this for a pal's wedding dinner), as a sauce or chutney with roast pork loin; as a dessert on their own with a dollop of crème fraîche (What? Are we supposed to be watching our fat intake? Okay, then, non-fat Greek yogurt with a little vanilla extract stirred in.). How about a little sorbet? That's light and healthy: Thin the puree with rosé wine (or cream and the thickness of the puree gives you ice cream without needing to make a custard) and

Cooks' Happy Hour, cont. on page 19



freeze in an ice cream machine. You can also make a classic, old-fashioned American dessert, a fool – whip heavy cream until stiff and fold in the plum purée.

Roasted strawberries or raspberries: Make a syrup with equal parts honey and water or two parts sugar to one part water and simmer with perhaps a little freshly ground pepper (Recently I've discovered cubeb pepper and long pepper from Indonesia and they are amazingly good) or allspice. This year I've discovered how good rose geranium is with berries – rub the leaves of a sprig, drop it into your syrup and let steep until you can taste the flavor. Toss the syrup with the berries, making sure not to drown them in syrup, pour them into a baking pan, and put in a slow oven. Roast until they lose about half their volume but be careful not to overcook or the berries will get leathery. Good for snacks out of hand but too tough to top cheese. Freeze your roasted berries and use them to bring back sunny days at breakfast and to serve with cheese or over a toasted slice of brioche or cake in the afternoon. (Can you tell I cannot keep focused on “health”? I've just completed the manuscript for a French cookbook. I blame that.)

Roasted peaches are really great and when you take a container from the freezer come February, you will be glad

you made an effort. Really. And it's a good way to give late-season peaches more flavor. They can release a lot of juice as they cook so make sure not to overfill the baking sheet: Peel and thickly slice about five pounds of peaches and toss with the juice of one large lemon or two Meyer lemons. Place two tablespoons butter in a small saucepan with two Turkish bay leaves torn into pieces and one minced rosemary sprig. Heat over medium heat until the butter browns. Stand back from the pan as you stir in 1/3 cup white balsamic vinegar (Do not substitute dark balsamic; you will wreck the color!) and 1/3 cup brown sugar. Stir well until the sugar has melted, and then pour the mixture over the peaches. Toss well but gently so as not to break up the fruit. Pour onto a rimmed baking sheet and spread the fruit out into an even single layer. Roast in a 250°F oven for 1 hour. Turn the slices and roast another hour. Turn again and roast a third hour. (Hopefully, you were not planning on serving these for happy hour tonight.) Turn again and roast until dried to desired level. Remember to pull a slice out and let it cool a bit to properly test it. You can adjust the time and temperature to suit your schedule. For example start out as described for one or two hours and then reduce the heat to 150°F and let the fruit continue to cook overnight. I did them from 11 pm to about 6 am.

Our motto: Eat Well to Stay Well

FROM IWMF-TALK

BY MITCH ORFUSS

One of the nice things about summer is that, even after decades out of school, it still retains a reminder of “vacation” – unless, of course, it's in reference to IWMF-TALK. There's been no vacation from that, and it's a good thing for the more than 1,000 TALK readers and writers who depend on this online tool to ask interesting questions, seek others' opinions, and find community in the attempt to manage WM. You could call TALK “the social network for Waldenstrom's”! As the number of TALK readers and their breadth of interest continue to grow, TALK serves an ever more useful role, as evidenced by just a few of the most TALKed-about topics.

Peripheral Neuropathy

Mike Dewhirst wrote: “As some of us may at some point experience peripheral neuropathy, studies that have been done may be of some interest to those who wish to improve functionality, strengthen muscles, and start alleviating their PN problem through various strengthening exercises.” According to one study cited by Mike, “strengthening exercises were found to reverse the losses in muscle strength related to peripheral neuropathy.” Studies also show significant improvements in such outcomes as stance, functional reach, and motor conduction velocity as a result of progressive resistance exercise, aerobic exercise, and stretching.

Megan Davey replied, saying she hadn't thought of this before but supposed it made sense, since PN due to the damage of the nerves can lead to muscle loss. **Malcolm Walpole** said that he too has PN in his feet, the result of thalidomide therapy followed by bortezomib (Velcade). The PN has lasted for more than four years, and Malcolm's oncologist thinks it is by now irreversible. He takes pregabalin (Lyrica), which takes the edge off the pain. More importantly (his words), Malcolm wears Sketchers Shape-ups, similar to MBT Shoes with their rounded soles but less expensive. They really do help, he says, in keeping the lower leg and ankle muscles toned, and are much more comfortable to walk in. Malcolm can walk for hours in them, whereas he has to stop after an hour when in ordinary shoes.

Jack Whelan noted that **Dr. Fred Hochberg**, a well-known neurologist at Massachusetts General Hospital, has a keen interest in researching and treating neurological issues associated with WM and has been studying the effects of chemotherapy and the treatment of PN and other neurological complications. Jack met with Dr. Hochberg and his team several times. Perhaps the most interesting question yet to be resolved: If chemotherapy can cause the nerve damage in our

From IWMF-Talk, cont. on page 20



feet that so many of us experience, what other types of nerve damage might be caused elsewhere in the body?

[Dr. Hochberg spoke at the June IWMF Educational Forum in Minneapolis. His presentation is included in the Forum DVDs and a summary is found in the Ed Forum Review: 2011]

Sharon Potesman wondered if anyone had success treating PN caused by WM but not attributable to Velcade or any other treatment. Sharon had one round of four Rituxan treatments that brought her IgM down and hemoglobin up but did not relieve the PN. **Dr. Jacob Weintraub** suggested that Sharon's IgM is still too high to relieve her PN, if indeed the neuropathy is truly related to her WM. "Some of us," Jacob offered, "have PN that started when our IgM was below 1000. Sharon's IgM may need to be much lower than it is now." Jacob added that nerve regeneration is a slow process. When IgM is lowered significantly, it may take months before improvement is noticed. Finally, Jacob recalls Dr. Treon's comment that if a person has had PN for a period of time greater than two years it may no longer be completely reversible.

Platelets

Sara "eyeonthesky" writes that her 84-year-old father's platelet counts are slowly decreasing – now at 114 (thousand). Sara asks at what point would he need treatment to bring platelets up? He has no bleeding problems yet.

"Linda54jane" responded that she has ITP (idiopathic thrombocytopenic purpura) with low platelet counts. Her hematologist is not concerned as long as platelets remain above 20 (thousand). "I would need treatment for any surgical procedures, but risk of spontaneous bleeding is low. When they drop below 20, the hematologist will prescribe IVIg to bring them to a safer level," writes Linda Jane. The infusion is costly, but it has brought her platelets back to normal, with a gradual decrease over months. "I would not want or seek treatment at 114 (thousand)," was her final comment.

Eye Migraine

Scott K had a visual problem for about 25 minutes on the day he wrote. He experienced wavy, pain-free distortion and flashes in one eye, and although Scott could still see things, everything in that one eye appeared as if he were looking through a wavy liquid. A friend of Scott's who works for an optometrist said that these are called eye migraines, that they are somewhat common, and that if they are not accompanied

by pain or other effects then not to worry. Scott wondered if WM was influencing or causing this visual problem.

Marla Kressall asked Scott: "Do you know your viscosity level?" This exact thing happened to Marla's husband. Somehow his viscosity had not been measured and it turned out to be high: 4.0. Marla had to take over the driving one day from her husband because he was seeing "something wavy." Marla knew immediately he needed plasmapheresis (PP). His doctor sent him to a retinal specialist, who confirmed Marla's "diagnosis." After the PP her husband's vision improved only slightly, possibly because it took three days to get the PP done.

Art Mulholland then added that he has had eye migraines since 1999. In Art's case, what he calls the "neon distortions" move from left to right, last approximately 15 minutes, and are preceded by slightly blurred vision. The ophthalmologic neurologist he consulted believed that Art's migraines could have been caused by the Waldenstrom's. Apparently they are common and are not serious unless they last longer and are accompanied by pain.

Bernice Goll joined the discussion, saying that as an optometrist it is her understanding that ophthalmic migraines are triggered in the same way as migraine headaches: there is a reversible constriction of blood vessels in response to some chemical trigger. These chemical triggers can be external – such as caffeine, red wine, or aged cheese – or internal – hormones, for example. These migraines are generally felt to be benign. Most people will have the experience at least once in their lives, though some are more prone to having them. Bernice recommends getting a dilated eye exam, especially if symptoms occur in only one eye. WM can lead to eye-circulation problems, which should be checked out. Bernice offered that eye doctors generally do not associate the phenomenon with a serious condition. But she is always a bit suspicious upon hearing that it has happened to someone with no history of headaches, especially if it comes on suddenly and with frequency.

Nosebleeds

Kierin DeArmand wrote regarding her husband who was diagnosed in 2004. So far he has been asymptomatic and has had no treatment. However, in the last 6 months he has had nosebleeds that can last for hours, and in the last 2 months they have been much more frequent. And he has

From IWMF-Talk, cont. on page 21

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



had cauterization. Kierin asked how others have handled nosebleeds that can arrive without notice. Has anyone started treatment for WM due to nosebleeds?

Bryan Crawford replied that he too experienced severe nosebleeds – before diagnosis. Bryan also felt weak and his legs hurt when he stood up. WM was discovered after blood testing for irregular heartbeat. “My IgM was 10,100,” reports Bryan, “and hemoglobin was 7.7. I was sent to Wake Forest Medical Center in Winston Salem, NC, where they decided to start treatment immediately – fludarabine and Rituxan x6 rounds of treatment. Nosebleeds stopped after the initial round of treatment. Currently on Rituxan maintenance.”

Peter DeNardis added that in the spring and summer 2003, before he was diagnosed, he experienced frequent and severe nosebleeds. He had a history of nosebleeds, but these were “blood fountains” that took some time to get under control. Peter shrugged it off – thought perhaps he was working too hard and had developed a sinus infection. Then he started having night sweats; he ignored them as well. An unrelated blood test led Peter to his WM diagnosis.

Carl Unger said he also had spontaneous nosebleeds before diagnosis in May of 2008. In addition to IgM of 8,500 and SV near 10, they found cold agglutinins and acquired Von Willebrand disease. Carl’s oncologist first insisted on PP so that a Rituxan flare wouldn’t put him at possible risk, then treatment on the clinical trial of Rituxan and Velcade which eventually got Carl’s IgM down to 2350 and his SV down to 2.5. Now he is negative for the acquired Von Willebrand’s and

has had no more nosebleeds. However, he still has an issue with the cold agglutinins, and this makes blood tests highly unpredictable at times. Carl had just finished six rounds of Rituxan and bendamustine and reported feeling better than he had in ten years, with IgM down to 1780 and SV to 2.5. Carl closed by expressing gratitude to his medical team and the miracles of modern medicine.

A Promising Novel Agent: PCI-32765

David Sellers, one of the earliest WM trial participants in PCI-32765, wrote in praise of this new drug. Having passed one year on the drug at the end of April, David’s most recent blood test showed IgM dropping below 1,000 for the first time since his diagnosis a decade earlier. All of David’s CBC numbers were in the normal range (with Hg at 14.9), except for platelets, which were a bit low. Carl called PCI-32765 a miracle drug that gave him back his life. **Joe Dunn** posted that he started on the PCI-32765 trial 10 months ago with an IgM of 5500, is now down to 1000, and expects to remain on the drug for the foreseeable future. Joe’s blood counts are normal or near normal, and he’s experienced no adverse side effects.

And Much, Much More

Other TALK topics that popped up from time to time included: timing between plasmapheresis and treatment, urine testing, stem-cell harvest and transplantation, transfusions, treatment timing, lidocaine patches, and so much more. If it’s about WM, it’s probably on TALK! Until next time, here’s to good information to all who seek it and best of health to everyone.

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

CALIFORNIA

Sacramento and Bay Area

The Sacramento and San Francisco Bay Area support group held a meeting in the Roseville Kaiser Hospital and discovered great enthusiasm for meeting closer to Sacramento than the usual meeting place of Vallejo. Eighteen people formed a good circle discussion, shared refreshments, and enjoyed the DVD of Mayo Clinic’s Dr. Morie Gertz’s talk, “The Garden.” Another sizable contingent liked the idea of the Roseville rendezvous but could not attend. Plans are now to hold meetings alternately in both Roseville and Vallejo. In September at the Vallejo Kaiser, members who had attended the IWMF Ed Forum in Minneapolis reported on their impressions. There was also time for personal interactions and refreshments.

CONNECTICUT

The Connecticut Yankees gathered on Sunday 12 June in the town library in Westport. Newly diagnosed WM patients as

well as “regular” attendees shared their personal experiences. Videos from the Fourth Patient & Physician Summit held in March in Orlando were shown and focused on Dana-Farber’s Dr. Steve Treon’s presentation, “Front-Line Treatment Strategies.” At the conclusion of the meeting, the group adjourned to a local eatery where members enjoyed renewing old acquaintances and making new ones.

FLORIDA

Ft. Lauderdale

Phil Lewis, co-leader of the group, led the fall 2010 meeting at the Memorial Hospital West. He summarized what he learned at the Bing Center Summit in Orlando the previous March and the June IWMF Educational Forum in Minneapolis. Dr. Daren Grosman led a question-and-answer session for members after the presentation. Dr. Grosman is the Director, Leukemia and Lymphoma Program, and Associate Medical Director, Memorial Cancer Institute, Memorial Hospital West. He attends all the meetings and arranges

Support Group News, cont. on page 22



for the meeting room. Light refreshments were served. Informative handouts provided by the IWmf Sarasota office were available for attendees to take home. Plans are afoot for Dr. Treon to make his annual presentation to the group in the December 2011 - January 2012 time period.

GEORGIA

Mal Roseman, group leader, is planning the fall meet-and-greet style meeting for 22 October.

ILLINOIS

Chicago Area/SE Wisconsin

The group held its much-anticipated annual summer picnic towards the end of August. **Sara** and **Mike Thran** welcomed everyone to their home in west suburban Chicago. The seventeen families totaling a small crowd of 31 delighted in the green lawn and the great burgers from the Thrans' own "home-grown" cattle as well as the delicious brats provided by **Don** and **Mary Brown**. The sun came out after a morning rain and encouraged good fellowship. Three new families were welcomed by the group and shared their recent journeys with WM. Everyone was saddened by the announcement by **Angelique Draftz** that her father, **Ron Draftz**, had received the last rites of the Catholic Church that morning. Ron was so special to this group and a larger than life leader within the WM community. Everyone will miss his presence and in-depth knowledge. The next meeting is planned for Saturday 22 October at the usual location, Advocate Lutheran General Hospital in Park Ridge.

INDIANA

Fifteen members of the newly formed group met in July for the second time in Indianapolis at the Leukemia & Lymphoma Society. A summary of the IWmf Educational Forum was given, followed by a question-and-answer period fueled by coffee and a light breakfast. The next meeting is set for 29 October to view selected segments of the IWmf Educational Forum DVDs. As before, the meeting will be from 10:00 am to noon with breakfast snacks provided by the LLS. The group decided to avoid the potentially hazardous winter travel conditions and scheduled a spring meeting on 31 March 2012 with Dr. Rafat Abonour, the hematologist and expert in multiple myeloma who presented on stem cell transplants at the recent IWmf Educational Forum in Minneapolis, as the guest speaker. Dr. Abonour is the Director, Indiana University Simon Cancer Center, and Associate Dean of Clinical Research, Indiana University School of Medicine.

NEW YORK

New York City

The July meeting was very well attended. The discussion

once again centered on the growing number of new single agents and combinations that are being added, one at a time, to the standard WM-fighting arsenal following results from the many trials that show such great promise. The discussion gave rise to a growing sense of gratitude for the work of the many professionals worldwide who have so significantly improved the treatment picture since the turn of the 21st century. The difference is like night and day. Anticipation is already building for the November meeting. Dr. Richard Furman, whose growing practice at Weill Cornell Medical College and New York-Presbyterian Hospital focuses on WM, has graciously agreed to talk with the group about the latest news from the encouraging trial work he is leading. There is not likely to be a spare seat in the house, as patients from adjacent support groups will undoubtedly try to crash this party! And they are most welcome, too.

NORTH CAROLINA

The North Carolina support group met in August in downtown Charlotte. This was a first effort to expand the "service area" beyond the normal meeting locale of Hendersonville, in western North Carolina. Although the turn-out was modest, an enthusiastic group included three new members. The speaker was Dr. Reza Nazemzadeh, an oncologist-hematologist in the Mecklenburg Medical Group in Charlotte. Dr. Reza, as he is known, gave a brief overview of WM, its symptoms, and his philosophy for treatment: "treat the symptoms, not the numbers." He stressed that it is important for each WM patient to be his or her own advocate during treatment. We then enjoyed an extensive question-and-answer period with the doctor. For the benefit of new members, **Don Nolan** gave a synopsis of previous meeting programs. **Tim Brown** presented his impressions, all of which were positive, of the International Patient and Physician Summit on Waldenström's Macroglobulinemia held this past March in Orlando. Thanks go to **Rick Tobar** for coordinating the meeting and providing refreshments.

EASTERN OHIO, WESTERN PENNSYLVANIA & WEST VIRGINIA

After a winter hiatus, members gathered at the home of **Marcia** and **Glenn Klepac** for a late spring potluck and meeting. Plans were to view a video of the WM Summit in Orlando; however, after so many rainy spring days, no one seemed anxious to leave the beautiful sunshine and go inside to watch a DVD. Instead, members socialized and shared WM stories along with an array of other health concerns. As usual, the food and drink contributions were a big hit that certainly added to the relaxed atmosphere on the patio.

Support Group News, cont. on page 23

NOTICE: From now on the Lifeline List and the List of Support Group Leaders will be published twice a year, in the *Torch* issues mailed in January and July. Up-to-date listings available at www.iwmf.com



Concluding thought: sometimes it makes sense to “go with the flow” and let the group guide the agenda.

OREGON/SOUTHWEST WASHINGTON

Here is a report from the Oregon and SW Washington IWMF and LLS Support Group written by **Joel Rosenblit**: Contrary to common belief, it does not rain all the time in the Pacific Northwest! A beautiful summer day may have caused a smaller than usual group to gather for our quarterly meeting in July. However, those who attended were rewarded by a stimulating presentation by Mark Bricca, N.D., about naturopathy as a complementary treatment for WM in conjunction with medical options. He emphasized nutrition, lifestyle, and botanicals to strengthen the body’s wellbeing and ability to fight cancer. The group was so involved and full of questions for Dr. Bricca that the meeting ran over its scheduled close. Afterwards members lingered to renew friendships and share the latest experiences with WM. Several members are involved in clinical trials for RAD 001 and CAL 101 and reported positive responses. The group is a partnership with the local LLS chapter and the IWMF and is pleased to learn that Dr. Treon will be speaking at the next meeting on 22 October from noon to 2:00 pm in Lake Oswego. The first time Dr. Treon presented, people arrived from California, the southern Oregon coast (six hours away!), and northern Washington (5 hours).

PENNSYLVANIA

Southeastern PA/Harrisburg Area

As group leader **Terrie Eshleman** watched the hurricane Irene warnings, she realized that the much-anticipated annual picnic scheduled for Sunday 28 August had to be cancelled. The next meeting will be at Messiah Village on the second Sunday in November.

SOUTH CAROLINA

The next meeting of the South Carolina WM support group will be held on Saturday 3 December, from noon to 2:30 pm, at the Greenwood Country Library, 600 Main Street, Greenwood, SC. New WM patients and their families as well as “veterans” will socialize and share individual experiences along with light lunch items and holiday refreshments.

TEXAS

Houston

The next meeting is to be held Sunday 13 November, at 2 pm, 21 Briar Hollow Lane, Briar Room, Houston (in the Galleria-Uptown area, inside the loop, between San Felipe and Post Oak Boulevard). We will have a speaker – physician and subject to be announced later. As usual, there will be delicious refreshments.

THE INTERNATIONAL SCENE

AUSTRALIA

It’s been a quiet three months for the WMozzies, which is not uncommon. There are very large distances to cover for members to meet face to face. The local e-mail discussion forum is valuable for comparing notes and conveying thoughts or experiences to new members or some who may have a major difficulty at hand. Social chatter is a little against the national character at our age group and many people also use IWMF-Talk, the main IWMF talk list. So this period was like most others.

Nicole Douglas, our support service coordinator for WM in Australia (Leukaemia Foundation of Queensland) attended the Minneapolis Ed Forum in the USA. She reports, “The Forum was wonderful and gave me a lot more insight into the disease as well as the concerns of those patients and their families affected by it.” This is great since there are now direct enquiries from patients coming to Nicole. Others come to our group via the local website www.wmozies.com. It’s very pleasing to report that our members show great understanding and sensitivity to the questions being posed. Why wouldn’t they? Once you begin walking this road you are changed forever. Still, it is great to observe.

CANADA

Arlene Hinchcliffe, President of Waldenstrom’s Macroglobulinemia Foundation of Canada (WMFC), is excited to introduce the new website for the Canadian chapter of the IWMF. The Canadian website www.wmfc.ca provides an easy way to find the information you are looking for in Canada and works in tandem with the IWMF website, which offers in-depth information about the disease.

The website allows both the convenient payment option of PayPal and the mail-in option for donations to the Membership Fund, In Memory of, In Honour of, and to the Research Fund.

Members of the WMFC automatically become members of the IWMF, therefore all Canadians should forward their donations to the WMFC to receive a tax receipt.

All 182 members are asked to reach out to their communities through doctors, clinics, and hospitals to be sure no one who is diagnosed with this rare cancer is alone.

For more information on participating and supporting the WMFC/IWMF, contact Arlene at wmfc@noco.ca

The International Scene, cont. on page 24



Throughout 2011 member donations to the WMFC continue to support research at the BC Cancer Agency to develop an immune response in patients with WM. The researchers believe that a successful immune-based therapy will require targeting of multiple aspects of the WM tumor. Those aspects to be targeted are currently being identified in a number of patients with WM. Recent developments in scientists' ability to sequence genes will enable mutations specific to WM to be identified. Once these specific mutations are identified, an agent can then be developed to target them. The chapter looks forward to the final report on this research project in the near future.

NEW ZEALAND

"Hello from the Waldo's," that's the WM's of New Zealand. They have a meeting arranged for 5 November at Palmerston North where one of the clinical haematology specialists, Dr. Bart Baker, will present "A Summary of Waldenstrom's and its Treatment." After a short discussion, the group intends to have a meal together. There are only about twenty known WM patients in New Zealand and the group arranges few meetings. Members live as far north as North Auckland and as far south as Southland. That is the best part of 2000 kilometers apart. Palmerston North is about the halfway point between, so the hope is for a good attendance.

Survivorship in Cancer, cont. from page 2

in allogeneic transplants; surgical procedures; hormone manipulation.

A recent study has demonstrated that certain kinds of chemotherapy can change the brain's metabolism or decrease cerebral blood flow – and these effects may linger up to ten years post treatment. In some patients, chemotherapy triggers a demyelinating degenerative condition in the central nervous system disrupting normal nerve signaling (akin to peripheral neuropathy).

Impact of chemo brain

For some patients, chemotherapy treatments will result in difficulties with thinking, memory, planning, and word finding. Although the brain usually recovers over time, the vague and at times distressing mental changes cancer patients notice are very real. Chemotherapy-related cognitive changes may result in patients being unable to return to school, work, or social activities, or make it exceedingly difficult to do so. Patients who notice difficulties with cognitive function may feel estranged from their loved ones and may even feel quite upset if their physicians dismiss their symptoms as "nothing to worry about" or ascribe them to the "normal aging process."

Research in chemo brain

Chemo brain is clearly difficult to study. Lack of standardized testing for cognitive ability, absence of pre-chemotherapy cognitive testing, and very subtle changes that are not readily apparent – all make objective evaluations challenging, particularly when the tests used in the studies are not sensitive enough to pick up smaller changes in cognitive function. Nonetheless, chemotherapy is now viewed as a known cause of brain problems in some people with cancer. Many of these people have cognitive difficulties that are directly related to cancer or its treatment, and many of these problems do not show up on testing.

Not all cognitive changes occur at the same time as well. Many cancer treatments, including chemotherapy and radiation,

can cause short-term, long-term, and delayed problems. Researchers have tested brain function a few weeks, a few months, or even years post treatment. Changes lasting only a few weeks with no long-term changes can be missed by late testing, and changes lasting greater than a year may not be evidenced by testing that terminates at six months. Some chemo brain symptoms are only noticed once treatment is over and worsen over time.

Medical imaging studies have shown that the areas of the brain that deal with memory, planning, putting thoughts into action, monitoring thought processes and behavior, and inhibition (namely the frontal, parietal, and temporal lobes and the hippocampus) are smaller after chemotherapy in some patients. In other studies, these changes appeared to be more pronounced in patients undergoing high-dose chemotherapy (used for stem cell or bone marrow transplant for example).

However, a recent study of patients tested before stem cell transplant determined that certain changes had started before the transplant and that memory gradually improved markedly over the next eighteen months. Other studies have shown that cognitive difficulties present two years following treatment were much improved four years post treatment.

In patients who underwent a donor allogeneic stem cell transplant and received high-dose chemo and immune-suppressing drugs, researchers tested cognitive function soon after transplant and five years post transplant: despite improvement in cognitive function, greater than 40% of patients continued to experience some form of cognitive impairment. Although the patients improved in all areas tested, important deficiencies were noted in hand speed, dexterity, and word recall.

In addition, brain scans of breast cancer survivors treated with chemotherapy (compared with breast cancer patients not treated with chemotherapy) showed changes five to ten years post treatment.

Survivorship in Cancer, cont. on back cover



THE “NEW” WEBSITE IS ONE YEAR OLD!

BY PETER DeNARDIS, IWMF WEBMASTER

It's now one year since the new IWMF website was unveiled. The intent has been, and continues to be, to provide valuable information about Waldenstrom's macroglobulinemia to the IWMF community (patients, caregivers, and health professionals).

On the website, one can find information about the IWMF, about WM, about treatments, and about how to live with the disease. Of particular interest are items such as:

- Descriptions of and links to clinical trials
- Information regarding researchers at the major WM research centers
- A WM glossary of commonly used words and abbreviations
- Support groups in your area
- Phone/e-mail contacts for advice regarding symptoms and treatments
- Recent medical journal articles about novel treatments and study results
- DVDs of recent Ed Forum and other symposia proceedings
- Instructions for joining various WM-related online discussion groups

We should all feel free to explore, read, reread, and revisit the various pages on the website, and not just stop at one visit! In that process, one can learn more about the disease and how best to live fully and happily with it (or perhaps, in spite of it). In turn, we will become empowered to be better patients and help ensure that we get the most efficacious treatment possible for our particular condition.

You'll find that the website content is updated frequently. On a given day, you might find new items in:

- Clinical trials
- News & events
- Journal articles
- IWMF-funded research
- Ed Forum information
- *Torch* publications in various languages

Further improvements are planned for the website in the near future, and include:

- An FAQ page (Frequently Asked Questions)
- Incorporating an upgraded version of online discussion list, IWMF-TALK, into the website
- Non-English language versions of the home page to make it easier to find the website regardless of one's country of origin or language.

The website has been designed to provide valuable assistance to as many in the WM community as possible. If you find something is missing, or you'd like to see more information on a certain area of interest, or if you just want to give constructive positive or negative feedback, please send your comments to the webmaster via e-mail to webmaster@iwmf.com

Website Stats - Since September 30, 2011, we've had:

- 18,593 visitors
- 36,000 visits
- 4 pages per visit
- 125,633 page views
- 01:44 minutes average time on page
- 200 to 500 page views per day
- 55% of the visits are new visits
- 15% of visits were from folks who had visited the site 10 times or more
- 5% of visits were from folks who had visited the site 50 times or more
- Traffic sources are: 43% search engines; 31% direct traffic; and 25% referring sites
- The most visited pages are:
 - Home page (24%)
 - About WM/Prognosis (3.5%)
 - About WM (3.3%)
 - Torch (3.2%)
 - Survivors (3%)
- Countries of origin of visitors:
 - USA – 22,900 visits
 - UK – 2,712 visits
 - Canada – 1,955 visits
 - Australia – 1,121 visits
 - France – 709 visits
 - Germany – 413 visits
 - Italy – 305 visits
 - Netherlands – 269 visits
 - India – 218 visits
 - Ireland – 206 visits
 - Japan – 160 visits
 - Spain – 154 visits
 - Belgium – 146 visits
 - Norway – 142 visits
 - Denmark – 137 visits
 - Hong Kong – 133 visits
 - Brazil – 123 visits



**SINCE JUNE 2011, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:**

In memory of Edwina Andersen:

Robert K. Andersen

In memory of Dr. John C. Bernloehr:

Grand Ledge Country Club Annual
Golf Scramble & Ann Lipkowitz

In memory of Arlou Brahm:

Jane Giedraitis
Sue Wetherill Holsman
Warren & Doris Osterndorf
Suzanne Spindler

In memory of Joan Brewer:

Malcolm Brewer

In memory of Dr. Blythe K.V. Brown:

Marina Skulsky

In memory of Opal Brown:

Bradd & Linda Thompson

In memory of Violet Bruckner:

Sandy Benson
David & Barb Bruckner
Dorothy Bruckner
Ron & Ann Bruckner
Ron & Lauri Charvat
Mr. & Mrs. Del Chipps
Kim Corcoru
Bob Dostal
Frank & Jo Dufek
Lisa Flanigan
James & Marni Hamilton
Mr. & Mrs. Tom Hamilton & Sons
Mr. & Mrs. Bob Kalasky
Paul & Marylou Krajicek
Ruby Krajicek
Mr. & Mrs. Sunha Lim
Max & Nancy Maust
Mike & Dodie Michel
Mr. & Mrs. Phil Miller
John & JoAnn Munnelly
Bruce Noble & Mary Beth Bruckner
Larry & Linda Orsi
Steve & Ellen Short
Mr. & Mrs. John Sidzyk
Alice Stanek
Mr. & Mrs. Larry Stanek & Girls
Gordon & Nancy Wickham

In memory of Nick Carrick:

Arlene Hinchcliffe

In memory of Stan Casey:

Bill & Margaret Akana

In memory of O. Eric Cedergren:

Paul & Ione Cedergren Family
Ruth Henderson
Ernie & Nancy Huntzinger
Russ & Peg Koster
Barry & Sue Mueller
Helen Mueller

In memory of Jay Curtis:

Kaila Curtis

In memory of Marshall E. Davis:

Friends & Coworkers
of Mary Ann Chartrand

In memory of Ruth Dionne:

Bradd & Linda Thompson

In memory of Ron Draftz:

Robert K. Andersen
Jean Arndt
Philip & Francisca Bares
Dr. & Mrs. William Becker
Michael & Sue Berndt
Mr. & Mrs. Donald Bianchi
Massimo & Deborah Bosco
Mr. & Mrs. Craig Boyd
Dolores Brazas
Jerry & Barbara Britschgi
Dahla Brown
Susan Brown
Genevieve Burba
Albert & Sandy Burba
Kathie Cleary
Phyllis Costello
Terry & Wendy Denton
The De Witt Family
Diane Dierks
Mr. & Mrs. E. M. Donahue
Helen Eames
Hubert & Jacqueline Edfors
John Eldridge
Charlie & Peggy Emerson
Laurie Faulkner
John & Maureen Feller
John & Linda Gebhard
Mr. & Mrs. John Gibbs
Jack & Jani Graziano
Gene & Elena Griffin
Suzanne Herms
George & Dorothy Hoffmann
Ed & Barbara Hoskins
The Kalweit Family
Mr. & Mrs. Conrad Kotowski
Dr. & Mrs. Robert Kyle
Roy & Melanie Langhans
Dan & Annette Lydon
Neil & Joyce Massoth
Michael & Gerri McDonald
Alice Milota
John & Donna Nemsick
Vel Pieper
Sharon Potesman
Patricia Razook
Louis & Gisela Regganie
Alice Riginos
George & Sandra Ruppert
Alberto & Cynthia Savage
Larry & Barbara Schnurr
Mr. & Mrs. Mark Shalett
Mary Jane Stevens
Mr. & Mrs. Edward Sudlow
Jeanette Urbain
Joy Washburn
Brandi & Katherine Witt

In memory of Jeffrey Eickhoff:

Philip & Ann Baatz
Marna Lou Bechtol

In memory of Jeffrey Eickhoff (cont.):

Janet Creager
Vicky Delventhal
Mary Eickhoff
Marvin & Marilyn Elling
Richard Elling
David & Jackie Fouty
Kevin & Kelli Good
Douglas & Elaine Hines
James & Deborah Hoops
Harold & Jo Ann Jennings
Beverly Junge
Douglas & Sara Lippus
Cathy Mansfield
Betty Marihugh
Patrick McColley
Lanny & Gail Meyer
Thomas & Paula Moriarty
Clement & Joan Moser
James & Laurie Moser
Jerry & Pamela Nagel
Napoleon High School Tennis
Duff & Connie Jo Parker
Linda Parker
Thomas & Jeannette Parker
David & Nanette Reel
Jo Evelyn Schwaiger
Andrew & Carol Small
William & Terri Snyder
Dr. & Mrs. Edmundo Somoza
Philip & Susan Spieth
Stewart & Linda Stover
William & Diana Vocke
Ronald & Lori Jo Weber
Marvin Zumfelde, Jr.

In memory of Earl Fray:

Jerry & Barbara Britschgi

In memory of Jack & Carol Gelber:

Jed Gelber

In memory of Monique Godard:

Lise Chaput
Frank & Jan Jones

In memory of Arnold H. Goldberg:

Muriel Goldberg

In memory of Patricia Hansen:

Stephen Clark
Miriam Ganesh
Friends at HuntonBrady Architects
Rogers, Lovelock & Fritz, Inc.
Elizabeth Spangler

In memory of Jerry Harris:

Pat O'Neil-Moergeli

In memory of Robert Hesse:

John & Renee Addario

In memory of Steve Hlady:

Ken & Maureen Hlady

In memory of Elinor Howenstine:

Tom & Susan Howenstine

In memory of Gary Hughes:

Tammy Kennedy



SINCE MARCH 2011, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

In memory of Gary Hughes (cont.):

Steve & Julie Long
Sally Morton
The Zuber Family

In memory of Jack Hutchins:

Audrey Anderson

In memory of Yvon Lacroix:

Chanta Crevier

In memory of Marsha Lipman:

Fred Lipman

In memory of Judith Ann Longino:

James Carns

In memory of

Mary Agnes McCrimmon:

Shirley C. McIlmoyl

In memory of Rudy Moergeli:

Pat O'Neil-Moergeli

In memory of Judy Nolting:

Earl Nolting

In memory of John Peckinpaugh:

Jim & Pat Cole
Terry & Sue Dingee
Richard & Kathleen Donnelly
Kathie Fazekas
Isabella & Francie Heard

In memory of John Peckinpaugh (cont.):

Glenn & Meredith Higgins
Demetrios & Betsey Lappas
Thomas & Susan Manuel
Douglass McNeilly
Will, Lindsey, Erik & Kevin Mild
John A. Newton
Jon O. Newton
Julius & Cecilia Passalacqua
Passarella & Associates, Inc.
Paul & Vicki Spinelli
Dan & Geraldine Thurman
United Agencies Insurance Group

In memory of Anthony Piatkiewicz:

Mark, Lennore, James & Mark
Anthony Shubel

In memory of George Prill:

The Bryan & Valerie Bagg Family
John & Rachel Cate
Paul & Dorothy Gibson
Marjorie Heffner
Mr. & Mrs. Donald Jurenko
Ben & Judy Merry
The Mignano Family
Mr. & Mrs. H. K. Ulreich
John Van Velzer
Miriam Wade

In memory of Timothy Puhek:

Al & Carol Halloran

In memory of Phyllis Sawyer:

Audrey Thompson

In memory of John Edward Slattery:

Lynne Slattery Schroeder

In memory of Don Souter:

Audrey Thompson

In memory of Mari Ellen Stoddard:

Judy Workman

In memory of Harry Vaughan:

Linda Vaughan

In memory of Phyllis Weagant:

Donald Smith

In memory of Sybil Whitman:

Suzanne Herms

In memory of David Baker Winn, Sr.:

David Winn

In memory of Nicholas Wyman:

Mary Ann Morgan
Louis & Marion Roca
Beth Wells

SINCE JUNE 2011, THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

In honor of Tom Baker:

Frederick Baker & Family
David Gotwalt
David Martinelli

In honor of Larry Belcheff:

Debbie Yob

In honor of Tom Bommarito:

Bob & Lisa Bommarito
Carrie Bommarito
Tommy & Peppy Fahoome
Roman Jamrogiewicz
Kristina Marshall
Ray, Kim & Wally Miller
Richard & Dale Nolan
Celeste Traubert
Steve & Jeanne Yollick

In honor of the Chicago Area Support Group and Don Brown:

Erik, Erin, Cassidy and Gavin Brown
Mel and Aaron Tieman

In honor of Ron Draftz:

Louise M. Lee
Roy Langhans

In honor of Tom Fischetti:

Joseph Bianchi
Alton Davis
Pasternak Family Foundation

In honor of Stan Frankel:

David Horne

In honor of David Heiser:

Michael Dennis

In honor of Tara Hennessy, M.D.:

Michelle Felgar

In honor of

Jeremy & Arlene Hinchcliffe:

David & Nancy Rowell
Andrew & Margaret Stephens

In honor of Jack Honaker:

Dean & Sarah Fitori and Family

In honor of Jackie Macfarlane:

Kaye Boyle

In honor of Catherine McClounan:

Michael Iloo

In honor of Andree J. Miller:

Karl Miller

In honor of Christopher Moakley:

Julie Moakley

In honor of Michael O'Brien:

Matthew & Colleen Germann

In honor of Roy Parker:

Stu & Mary Kaye Parker

In honor of Mike Pennington:

Karen Blocksom

In honor of Anna Mae Quitter:

Janine Quitter

In honor of Donald Smith:

Kathleen Patrona

In honor of John Tiplady:

David & Kaye Gardner

In honor of Dr. Steven Treon:

Dan Stern





Mission Statement:

To offer mutual support and encouragement to the Waldenström's macroglobulinemia community and others with an interest in the disease.

To provide information and educational programs that address patients' concerns.

To promote and support research leading to better treatments and, ultimately, a cure.

Survivorship in Cancer, cont. from page 24

In patients suffering from chemo brain, newer studies using objective memory tests commonly reveal a decreased ability to learn new things, a marked increase in time required to recall prior information (executive function), as well as attention and concentration difficulties.

Treatment and coping with chemo brain

There are no known effective ways to prevent chemo brain at this time. For many cancer patients, chemotherapy treatments will result in cognitive difficulties. Researchers are actively evaluating treatment options that may protect the brain during and after chemotherapy. The newer targeted therapies that selectively focus on the cancer cells and spare normal brain and nerve cells may hold promise. Some researchers have speculated that genetic susceptibility for chemo brain may exist. Certain genes linked to Alzheimer's disease may predispose the cancer patient to increased risk of chemo brain. Medications now used for the treatment of depression, attention-deficit hyperactivity disorder (ADHD),

Alzheimer's disease, and dementia may one day be used as potential treatments for chronic long-term chemo brain.

In the interim, what can be done if a patient is experiencing chemo brain? Researchers who have studied memory suggest techniques such as avoiding distraction, using a daily planner, keeping a journal, posting reminders, setting up and following routines and keeping the same daily schedule, exercising your memory by doing crosswords or playing a musical instrument for example, managing stress with meditation and other techniques, getting enough rest and sleep, exercising on a regular basis, eating healthy, and finally trying not to obsess on how chemo brain symptoms are interfering with normal daily activity.

Chemo brain is but one of the many survivorship issues facing cancer patients. Accepting the problem and being able to laugh about things one cannot control may sometimes be the most successful coping mechanism of all.