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## PRESIDENT'S CORNER

BY JUDITH MAY



*Judith May, President*

As we enter the New Year, it is appropriate to look back at the past year and reflect upon the IWMF's many activities and also to look ahead at the foundation's plans for 2010.

### Changes to the Board of Trustees and Officers

Many changes to the IWMF Board of Trustees occurred over the past year with the departure of five Trustees: Jim Bunton, Jim Berg (deceased), Arlene Hinchcliffe, Dave Lively (deceased), and Roy Parker. We will forever miss our departed friends and colleagues, Dave Lively and Jim Berg. We are grateful for the fine efforts of all five trustees and the progress they helped the foundation to achieve during their time on the Board.

New Trustees added to the Board during the past year bring much-needed special skills and talents. The new Trustees are: Cindy Furst, Sue Herms, Marty Glassman, and Guy Sherwood, M.D. With recent additions to the Board we also added high-level computer skills, project management experience, scientific research backgrounds, and medical professionalism, making the IWMF Board of Trustees stronger than ever.

We still have need of skilled and experienced writers and editors. If this appeals to you and if you have experience with writing and editing, we would love to review your resumé. You may forward resumé to Sara McKinnie at the IWMF office, [info@iwmf.com](mailto:info@iwmf.com).

At the November Board meeting, two vacant officer positions were filled. Bill Paul, our Treasurer, has also assumed the position of Secretary. Very often the position of Secretary-Treasurer is combined, particularly in small organizations like ours. Marty Glassman now fills the position of Vice President for Member Services. A relatively new Board member who brings long experience in project management, Marty will be a great help assisting in the updating of services and completion of projects in progress.

### Update on current projects

As you know, a new website for the IWMF has been in the works for some time. This is a huge undertaking that has required more time than anyone had anticipated. However, I am happy to report that the completion of the website is just around the corner. As soon as our contractors give us a date for going on-line, we will notify members. The website address will, of course, remain the same.

Another long-term project that encountered more complexities and delays than anticipated is the patient database. However, the database is alive and well, and the most recent report is that work will begin in January on the largest of the three modules remaining to be completed: treatments and drugs. As progress is made, there will be brief reports in the *Torch*. At this time we are not ready to announce a completion date.

In the near future we will print updates of two IWMF booklets. Dr. Guy Sherwood has re-written the booklet "Treatment Options" and Sue Herms, our Medical News Editor for the

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*President's Corner, cont. from page 1*

*Torch*, has re-written "Questions & Answers." With printing scheduled for early 2010, we anticipate that these booklets will be ready for mailing in the spring, if not sooner.

### A new service: WebEx

The IWMF Board of Trustees has approved the establishment of a WebEx account. We believe it will be very useful as an educational and communication tool for support groups, project teams, committees, and many other uses yet to be discovered.

WebEx is a Cisco Systems product that allows users in different locations to hear and see each other. One application especially useful for the IWMF: WebEx makes it possible for multiple support groups to view simultaneously a live presentation from one of the expert WM physicians or researchers.

The decision to open an account was finalized in November during our Board meeting where we experienced WebEx first hand and used it to have several ill trustees tune in from home and participate in the meeting. As you read in the last issue of the *Torch*, the Chicago area support group used this technology on a trial basis in August 2009 for a presentation and Q&A session with Dr. Irene Ghobrial, who spoke from the Dana-Farber Cancer Institute in Boston. The same support group was able to have a WebEx session in October with Dr. Robert Kyle, straight from the Mayo Clinic in Rochester MN. Used in this way, WebEx provides an opportunity for support groups to expand their meeting programs. In April at the Ed Forum we will be inviting support group leaders to another workshop and training in the operation of the WebEx system will be offered. We want to thank the volunteers at the Mayo Clinic and the Dana-Farber Cancer Institute for their wonderful help in making the presentations at the Chicago meetings possible.

### Strategic Planning Survey Forms

We were happy to receive the returned Strategic Planning Survey Forms – from all 59 of you who completed and returned them! However, forms were sent out to about 3,000 members and we are hoping that more of you would like to help the Board understand which services the majority of members use, how you rate these services, and if you would like to see revisions or new services in the future. Therefore, we are once again enclosing the survey form. So if you would like to sit down with a cup of coffee and

*President's Corner, cont. on page 3*



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### 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 Alice Riginos at 202-342-1069 or [ariginos@sy-thetis.org](mailto:ariginos@sy-thetis.org)

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.

take a half hour or so to give us your thoughts, we would very much appreciate it.

### **The 2010 Educational Forum**

Planning for the Ed Forum is moving forward for April 9-11 in Las Vegas. **However, we have had to make a change in our hotel choice.**

We learned of an unexpected and unfortunate situation at the hotel we had planned to use for the Ed Forum. Namely, that a large group of cigar smokers had reserved the hotel rooms, including 280 non-smoking rooms, for a 5-day cigar smoking vacation, departing only two days before we begin the Ed Forum. Due to our need for a smoke-free environment, we took action to quickly change the venue.

As an alternative, we have contracted with the J.W. Marriott Resort in Las Vegas. The standard room rate will be \$109 per night, (their normal rate is \$199.) This is a deluxe hotel with beautiful surroundings of giant palms and winding paths through gardens and along gentle brooks, passing by fountains, waterfalls, and pools. We have blocked sufficient guestrooms in one of the buildings, the Palms Tower, for the Ed Forum participants. The rooms are spacious with lovely furnishings and large bathrooms with Jacuzzi tubs and separate showers as well as walk-in closets and all the usual amenities. Each room has wireless (the rate is normally \$9.95 for 24 hours; however our rate will be half of that). There are six restaurants on the hotel grounds, an 18-hole golf course, pool, spa, shopping and a small separate casino in the back of the main building for hotel guests (not where we will be located). The vistas from the rooms include the Spring Mountain range, Red Rock Canyon, and beautiful desert sunsets. On Saturday night you have a free night to

enjoy the resort facilities, or you could visit the Las Vegas strip for dinner and a show on the free round-trip shuttles from the Marriott. The shuttles will run every hour from 5:00 p.m. until 11:30 p.m. If you plan to drive to the Marriott, free valet parking is offered to our group.

I can assure you this will be an unforgettable experience. The quoted rate is extended to us for three nights prior to the Ed Forum and three nights after the Ed Forum for those who would like to stay longer.

The program for the Forum is not yet complete, but I am pleased to announce that six WM experts are confirmed and will present information from the latest studies and clinical trials. They are: Dr. Stephen Ansell (Mayo Clinic, Rochester MN); Dr. Rafael Fonseca (Mayo Clinic, Scottsdale AZ); Dr. Irene Ghobrial (Dana-Farber Cancer Institute); Dr. Morie Gertz (Mayo Clinic, Rochester MN); Dr. Robert Kyle (Mayo Clinic, Rochester MN); Dr. Steven Treon (Dana-Farber Cancer Institute).

Ed Forum program information and instructions for registering at the Marriott will soon be posted on our website, and an e-mail message will be sent to members as well. The dates remain the same, April 9-11, 2010.

**If you have already registered with the Alexis Park Resort: you can cancel your reservation at no cost but should do so very soon.**

I hope to see many of you at the Ed Forum.

Stay well,

Judith

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## **RESEARCH UPDATE**

BY TOM MYERS, VICE PRESIDENT FOR RESEARCH

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### **Current Research Projects**

The IWMF is currently supporting two research projects: Dr. Steven Treon's "Comprehensive Studies into the Genetic Basis of Waldenstrom's Macroglobulinemia" at the Dana-Farber Cancer Institute and Dr. Stephen Ansell's "Factors Regulating Immunoglobulin-producing B-cells in Patients with Waldenstrom's Macroglobulinemia" at the Mayo Clinic. Dr. Ansell's grant was recently renewed for another two years because of the excellent progress he is making in identifying the cause of IgM production from tumor cells and the agents driving that production.

The status report received recently from Dr. Treon emphasizes the significant progress in understanding the genetic nature of the disease and the identification of some mechanisms that might lead to better treatments for WM patients. The following summary, issued by Dana-Farber, August 2009,

outlines the research undertaken by Dr. Treon and his team at the Bing Center and their very encouraging results to date:

Dr. Treon's studies have identified many genes that are expressed differently in WM patients compared to healthy volunteers. Some of these genes control cellular activities that are likely to be important in WM, and future studies will focus on learning how changes in the expression of these genes affect the growth and survival of WM cells. Dr. Treon has uncovered several potential explanations for why the genes are expressed differently. He has found that many small molecules known to influence gene expression are themselves expressed differently in WM patients versus healthy volunteers. Furthermore, two major processes that alter gene expression by chemically modifying DNA or the proteins that stick to DNA appear

*Research Update, cont. on page 4*

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to play an important role in WM. DNA mutations also undoubtedly contribute to the disease, and Dr. Treon has established a registry of WM patients and their families so he can look for such mutations in their blood and tissue samples. He has already identified several promising candidate mutations for further study. He has also found new ways to kill WM cells, either by exposing them to certain chemicals that trigger a particular kind of cellular stress or by interrupting communication between WM cells and other cells in the bone marrow. Together these findings offer hope that new medicines to treat WM are close at hand.

Dr. Treon's project, budgeted for \$1,038,942 over four years, is now nearing completion of the third year.

### New Research Initiatives

A grant request from Dr. Brad Nelson, Director of the Research Laboratories at the Deeley Research Centre of the British Columbia Cancer Agency in Vancouver, was approved for funding. The title of the project is "The Immune Response to WM: Implications for Immunotherapy." Following an approach used to develop a vaccine for follicular lymphoma,

Dr. Nelson and his group plan to identify genetic sequences that are specific to WM and then determine which T-cells react with the tumors. The Canadian affiliate of the IWFMF, the Waldenstrom's Macroglobulinemia Foundation of Canada, has agreed to fund this project. The grant request is for \$99,936 Can.

The IWFMF Board has also approved support for the development of a representative WM cell line in collaboration with the Leukemia & Lymphoma Society. In October 2008 the LLS held a workshop on Research on WM that was attended by more than 20 researchers and doctors. One of the main recommendations coming from the workshop was to develop a WM cell line that was stable and representative of the disease. A call for applications resulted in four proposals which are currently being reviewed by a committee of doctors and scientists. Depending on the quality of the proposals, up to four projects may be supported at a rate of \$100,000 per project for one year. At the end of the first year, a LLS/IWFMF review panel will decide which projects will be continued for two more years at a cost of \$200,000 per project.

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## IWMF RECEIVES AWARD FROM LYMPHOMA RESEARCH FOUNDATION

### A REPORT FROM THE LRF'S NORTH AMERICAN EDUCATIONAL FORUM

BY RONALD YEE, IWMF TRUSTEE

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*IWMF Trustee Ron Yee accepting award from Karen van Rassel of Lymphoma Foundation Canada and Suzanne Bliss of Lymphoma Research Foundation.*

It was raining hard on Friday evening as I left Philadelphia for the drive to NY to attend the Lymphoma Research Foundation's North American Educational Forum in Brooklyn, New York, held on October 24-26, 2009. From past experience I knew that the effort would be well worth it as the LRF has for many years been working in collaboration with the IWFMF to sponsor programs benefiting lymphoma patients and supporting Waldenstrom's macroglobulinemia patients.

Due to the infamous NY traffic and the weather, I arrived late for the welcome reception on Friday night but quickly recognized fellow WM patients who attend the New York and Philadelphia support groups. It was also a chance to meet other WM and lymphoma patients who were looking forward to the presentations that would be given over the course of the weekend.

Saturday morning brought continuing cold torrential rains, contrasting with the welcoming atmosphere that the forum gave patients – be they newly diagnosed or veteran patients. During the opening remarks, all forum attendees were sad to hear

the news that LRF President Suzanne Bliss was leaving the LRF to lead the National Arthritis Foundation. Over the years under Suzanne's leadership, the LRF has encouraged the education of WM patients by collaborating with the IWFMF and adding WM presentations to the various regional meetings it sponsors.

The first few sessions were of common interest for all lymphoma patients. Dr. Randy Gascoyne, British Columbia Cancer Agency, presented "A Pathologist's Perspective on Lymphoma." He explained how pathological studies are a key factor in the diagnosis and treatment of lymphoma patients, and his slides outlined some of the tools that the pathologist uses to make differential diagnoses affecting patient outcomes.

*IWMF Receives Award, cont. on page 5*



The next speaker was Dr. Stephanie Gregory, Professor of Medicine, Rush University, who spoke on “A Clinician’s Perspective.” Dr. Gregory’s presentation included a good overview of the genetic malfunction that causes lymphoma, some statistics about the incidence and causes of lymphoma, and the clinical presentation of a patient with lymphoma. She then presented on the treatment decision process and the possibility of enrolling in a clinical trial. Lastly, Dr. Gregory reviewed the mechanism of monoclonal antibody therapy and some new therapies being used in lymphoma treatments.

Dr. David Strauss, Memorial Sloan Kettering Cancer Center, presented “Where have we come from and where are we going to?” This talk covered various lymphomas and their treatment in years past versus current treatments with newer therapies. The take-away message is that there has been a marked improvement in patient outcomes with usage of the new therapies now available.

After the morning break, each of the interest groups for the different lymphomas met in separate rooms for focused presentations. The Waldenstrom’s patients heard lectures from three respected physicians in the field of WM.

The first WM speaker was Dr. Eva Kimby, Karolinska University Hospital, Sweden, who presented on the general biology of WM and the various treatment options available for WM patients. Dr. Kimby also spoke of the Bendamustine European trial and development of this compound from mustard gas used in wartime.

Luncheon was followed by the presentation of recognition awards given by the LRF. It was my distinct honor to accept

a collaboration award on behalf of the IWMF. This award is in recognition of the collaborative efforts of the LRF and the IWMF to further research for cures and to expand patient education.

The afternoon sessions continued with Dr. Richard Furman, Weill Cornell Medical College, presenting. Dr. Furman discussed the enhanced understanding of the mechanisms thought to be the underlying cause of WM. He then elaborated on the mechanisms behind current therapies and those in development.

The last speaker was Dr. Irene Ghobrial, Dana-Farber Cancer Institute, who spoke about exciting clinical trials and the results of these trials currently conducted at DFCI and at other centers around the country. Dr. Ghobrial also reported on novel drugs that are in the development pipeline.

In summary, the LRF Educational Forum held in Brooklyn was a very successful meeting for WM patients. As a Board member and a regular attendee of the NY and Philadelphia patient support group meetings, I was amazed at the number of newly diagnosed and veteran patients attending the meeting whom I had not met. It emphasized to me once again the importance of organizations such as the LRF and, most importantly, the IWMF in meeting the educational and patient support needs of the WM family and continuing the search for a cure for this disease.

Please take a moment to reflect on this and remember to join and support the IWMF!



### **IWMF BOARD VOTES TO SUPPORT INTERNATIONAL WM MEETING**

At the most recent meeting of the IWMF Board in November, the Board of Trustees voted to contribute funds to support the Sixth International Workshop on Waldenström’s Macroglobulinemia (IWWM 6), to be held in 2010 in Venice, Italy, October 6-10.

Support from the IWMF includes the expenses for a group of 10-12 younger researchers to attend IWWM 6. It is an important investment in the future of WM research to enable young up-and-coming WM researchers to participate in this pre-eminent international meeting devoted exclusively to the on-going study and treatment of WM. In addition, the IWMF will defray the cost of publishing the full report from IWWM 6 in one of the professional medical journals on lymphomas.

The Trustees also approved IWMF support of the second International Patient Forum to be held in Venice on Sunday, October 10, 2010, following the conclusion of IWWM 6. The IWMF joins the Dana-Farber Cancer Institute in sponsorship of the International Patient Forum.



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# THE IWMF INTERNATIONAL COMMITTEE

BY GUY SHERWOOD, M.D., INTERNATIONAL COMMITTEE CHAIRMAN

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In November 2006 the IWMF Board of Directors established a new committee to focus on the needs of WM patients outside the United States. The IWMF Board Book describes the IWMF International Committee as follows:

“The International Committee considers ways to increase awareness of the IWMF in other countries and to distribute our publications and extend our mission in countries outside of the United States. This committee will build coalitions and collaborations with appropriate organizations overseas and work with them to assist WM patients when possible.”

Roy Parker from Colorado was the first IWMF International Committee Chair from 2007 to 2009. Roy was instrumental in developing relationships with many individuals and groups from all over the world. The IWMF owes Roy and Eileen Parker a great debt of gratitude for their hard work and endless dedication.

With the advent of new technology, particularly the Internet, communication between WM patients all over the globe has become a reality. We already “talk” with our WM friends from England, France, Germany, Holland, Italy, India, Australia (including Tasmania) and many more countries through IWMF-TALK.

More recently the IWMF was proud to participate as a sponsor of the Fifth International Workshop on Waldenström’s Macroglobulinemia in Stockholm, Sweden, in October 2008. The first ever International Patient Forum was held the day following this prestigious meeting. A very interesting group of WM patients and caregivers from all across Europe met in the beautiful city of Stockholm to hear presentations from some of the well-known WM experts and have their questions answered, as well as to exchange personal stories about their particular WM journeys.

The IWMF, and specifically the International Committee, as well as our joint sponsors at the Bing Center, Dana-Farber Cancer Institute at Harvard, are already hard at work preparing for the second International Patient Forum which

will be held on October 10, 2010, once again on the day following the conclusion of the world-class International Workshop on Waldenström’s Macroglobulinemia (IWWM 6) in Venice, Italy. Judging from the numerous queries already received from WM friends, it certainly appears that a large number of individuals from all over the world will indeed attend this event.

International members, including Canada, account for 16% of all IWMF members. Canadians alone comprise 6% of those IWMF members from outside of the United States. Over 21% of the medical professionals who receive regular mailings from the IWMF are from countries outside the United States.

WM patients and caregivers from countries outside of North America have various types of support organizations. These range from support group organizations that are typically small to large networks of government-funded cancer organizations. The IWMF does not endeavor to take the place of these organizations but rather to assist them in their common goal: the education and support of WM patients and their loved ones.

To this end the IWMF is now embarking on an ambitious program that will hopefully help meet the needs of WM patients worldwide. These initiatives include, but are not limited to: many of our booklets and pamphlets will be translated into languages other than English; the renovated IWMF website will have home pages in various languages; the IWMF will assist in the development of new and existing “lifelines”; the IWMF will continue to participate in international cancer patient coalitions; and international patient forums, such as the upcoming 2010 International Patient Forum in Venice, will be developed and supported.

WM knows no boundaries; we are truly a global family. I look forward to assisting our IWMF Board and IWMF President Judith May, as well as all the WM volunteers from all around the world, to provide continued educational and support services to all WM patients, irrespective of where they live on this beautiful planet Earth.



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# THE VIEW ON VELCADE

BY SUE HERMS

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Velcade (bortezomib) is a fairly new drug in the arsenal of treatments for WM and is the first drug developed in the class called proteasome inhibitors. Much of the early work leading up to the discovery of proteasomes occurred in the late 1970s and early 1980s; however, the core of the proteasome structure was not determined until 1994.

What is a proteasome? It is a large protein complex found inside almost all cells, and its main function is to degrade unneeded or damaged proteins by chemically breaking them down with enzymes. Degradation of such proteins is a normal, necessary, and orderly cellular process. The structure of the most common proteasome resembles a barrel with a core of four protein rings stacked around a central opening referred to as the central pore. The core is “capped” on each end by additional proteins. Proteins are marked for breakdown by a small protein called ubiquitin, are partially degraded and unfolded, and enter the central core of the proteasome where enzymes break them down even further into peptides and amino acids, the basic building blocks of proteins. These amino acids can be recycled and used to make new proteins.

Why does a proteasome inhibitor such as Velcade work against cancer cells? Velcade contains a substance called boronic acid which binds to the core of the proteasome and blocks its enzyme activity, thus interfering with its ability to degrade proteins. Disruption of this normal protein breakdown process allows certain proteins in the cell to accumulate to the point where they can interfere with cell reproduction and other functions and lead to cell death (apoptosis). Preclinical studies of proteasome inhibitors showed that malignant and proliferating cells appeared to be more susceptible to proteasome inhibition than normal cells. Of course, as with almost all cancer therapies, there are side effects and the trick is to optimize the dosage to limit these side effects.

Velcade, originally called PS-341, was developed in 1995 and approved by the FDA in 2003 for the treatment of refractory multiple myeloma. It has since been approved as therapy for relapsed mantle cell lymphoma and as first-line therapy for multiple myeloma. It is marketed by Millennium Pharmaceuticals in the US and by Janssen-Cilag International NV in Europe. The use of Velcade in WM has become more widely accepted, especially in combination with other drugs.

Clinical response of WM to Velcade was first noted in a Phase I study of hematological malignancies published in 2002 in the *Journal of Clinical Oncology*. The earliest WM-only clinical trials of single agent Velcade were reported in 2004 and 2005. The dosage was by intravenous (IV) injection at 1.3 mg/m<sup>2</sup> on days 1, 4, 8, and 11 in a 21-day cycle. A Phase II study sponsored by the National Cancer Institute of Canada did not specify a maximum number of cycles, but a median of six cycles was administered; a multi-center U.S.

study attempted to administer up to eight cycles, but the median number of cycles delivered was also six. One of the most interesting observations from these studies was the increased incidence of peripheral neuropathy in WM patients receiving Velcade compared to that seen in multiple myeloma patients – this side effect was one of the most common reasons for limiting the number of treatment cycles. Fortunately, in most cases peripheral neuropathy was reversible when treatment was discontinued. Other common side effects included temporary myelosuppression (depression of the bone marrow) with decreases in cells such as neutrophils and platelets; and gastrointestinal problems such as nausea, vomiting, diarrhea, and constipation.

Although there are some obviously unpleasant side effects associated with Velcade, on the plus side it has shown promising results in the treatment of WM, particularly in the reduction of serum IgM levels. The earlier studies of single agent Velcade mentioned above had overall response rates (both minor and major) of 78-85%; however, there were no confirmed complete responses (complete absence of disease markers). Treatment responses were prompt, with partial responses occurring at a median of 1.4 months. This observation suggests that Velcade would be a consideration for those patients requiring rapid reduction in serum IgM. Another advantage of Velcade is that it is not toxic to hematopoietic stem cells and therefore can be used as treatment for patients who are considering stem cell transplantation as a future option.

Subsequent clinical trials have attempted to improve response rates and the number of complete responses by combining Velcade with other treatments. A Phase II clinical trial for WM using Velcade, dexamethasone (a corticosteroid), and rituximab (Rituxan) produced an overall response rate of 96% and, very importantly, a complete response or near-complete response rate of 22%. This combination is now referred to as BDR (for bortezomib, dexamethasone, and rituximab); however, as with the earlier trials, peripheral neuropathy was one of the most notable side effects encountered in this trial and, in some cases, limited the number of treatment cycles that a patient could tolerate. This combination therapy was also associated with a high rate of shingles, and prophylactic treatment with an antiviral is now recommended during treatment.

A slightly more recent Phase II study for WM combined Velcade and rituximab, but the Velcade dosage was changed to 1.6 mg/m<sup>2</sup> and administered once weekly, on days 1, 8, 15, and 22 in a 28-day cycle, instead of twice weekly. This reduction in the number of Velcade doses appears to have reduced the incidence of peripheral neuropathy; when it did

*The View on Velcade, cont. on page 35*





# THE BEN RUDE HERITAGE SOCIETY ENROLLMENT

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

Significant resources have been generated for IWMF through the Ben Rude Heritage Society by legacy gifts. More and more members and friends are asking about the Society so we thought we would reproduce the enrollment form here and cordially invite you to become a member of the Ben Rude Heritage Society. We are confident your legacy will prove to be an inspiration to others. We hope also that you will consider providing information about your legacy by completing the form below so we have a full understanding of your wishes. Use the enclosed envelope to facilitate your response. If possible, please attach supporting documentation. Thank you.

## **LEGACY GIFT**

I/We have arranged a legacy gift for the benefit of IWMF through my/our:

- Will
- IRA/Retirement-Plan Beneficiary Designation
- Trust
- Charitable Remainder Trust
- Other (please specify): \_\_\_\_\_

Additional Information: \_\_\_\_\_

## **DESIGNATION**

This gift is to be used for the following purpose: **(please check one)**

- IWMF's Greatest Need
- Research Fund
- Dr. Kyle Endowment Fund
- Fellowship Stipend Fund
- Other Named or Designated Fund: \_\_\_\_\_

## **GIFT DETAILS**

As of this date, the value of my/our gift is: the sum of \$ \_\_\_\_\_ or \_\_\_\_\_% of my/our estate or other gift plan, with the current value of the IWMF portion estimated at \$ \_\_\_\_\_. I/we understand that my/our estate **is not** legally bound by this statement of gift value.

## **RECEIPT OF GIFT**

This gift will be received by IWMF after the life of:

- The First Donor
- The Surviving Donor/Spouse
- Other Individual(s): \_\_\_\_\_
- Other Contingencies or Stipulations such as: \_\_\_\_\_

## **BEN RUDE HERITAGE SOCIETY HONOR ROLL LISTING:**

Name(s): \_\_\_\_\_

- Please enroll me/us in the Ben Rude Heritage Society using the Honor Roll listing above.
- Please do not list my/our name(s) in the Honor Roll and \_\_\_\_\_ in all other publications.
- Typically, IWMF recognizes Heritage Society membership with a recognition piece.

Check here if you prefer not to receive this token of appreciation.

Donor Signature: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Date: \_\_\_\_\_

Donor Signature: \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Date: \_\_\_\_\_

Please note that all information will remain confidential to IWMF. For further information about the Ben Rude Heritage Society, please contact Dick Weiland at [rjweiland@msn.com](mailto:rjweiland@msn.com) or 507.645.2633



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# MEDICAL ACUPUNCTURE: CONTEMPORARY USE IN MODERN MEDICINE

BY GUY SHERWOOD, M.D.

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*Dr. Sherwood's interest in the practice of acupuncture dates back some 20 years to his fourth year in medical school when he elected to work for a month with an anesthesiologist "who happened to do acupuncture one afternoon a week on difficult pain patients—I did not know what he was doing, but his patients loved him!" Following his successful stem cell transplantation in 2006, Dr. Sherwood enrolled in the medical acupuncture course conducted by UCLA exclusively for physicians. After six months of intensive study (plus final written and clinical examinations), he was accredited to practice medical acupuncture. Since August 2008 he has been doing medical acupuncture one afternoon per week at the pain clinic where he works. Cancer patients in active therapy are among those he has treated.*

## **ACUPUNCTURE: WHAT IS IT?**

Acupuncture is a natural healing system that encourages the body to promote natural healing and to improve function. Acupuncture is one of the oldest, most commonly used medical procedures in the world. Originating in China more than 2,000 years ago, acupuncture has grown in popularity in the United States over the past two decades. In 1993 the U.S. Food and Drug Administration (FDA) estimated that Americans made 9 to 12 million visits per year to acupuncture practitioners and spent as much as \$500 million on acupuncture treatments.

Medical acupuncture is acupuncture that has been successfully incorporated into medical or allied health practices in Western countries. As a therapy, acupuncture is used to prevent disease, maintain good health, and treat illness or injury. Derived from Asian and European sources, modern medical acupuncture is practiced in both pure and hybrid forms. The adaptability of classical and hybrid acupuncture approaches in Western medical environments is the key to their clinical success and popular appeal.

## **HOW DOES ACUPUNCTURE WORK?**

### **Classic Concepts**

The language in classic Chinese medical texts reflects nature and agrarian village metaphors and describes a philosophy of man functioning harmoniously within an orderly universe. The models of health, disease, and treatment are presented in terms of the patient's harmony or disharmony within this larger order and involve the responses to external extremes of wind, heat, damp, dryness, and cold, as well as to internal extremes of anger, excitement, worry, sadness, and fear. Illnesses likewise are described and defined poetically, by divisions of the *Yin* and *Yang* polar opposites (interior or exterior, cold or hot, deficient or excessive), by descriptors attached to elemental qualities (wood, fire, earth, metal,

and water), and by the functional influences traditionally associated with each of the internal organs.

The classical Chinese explanation is that channels of energy (*Qi* – pronounced *chee*) run in regular patterns through the body and over its surface. Traditional Chinese medicine theorizes that the more than 2,000 acupuncture points on the human body connect with 12 main and 8 secondary energy channels, called meridians. These are like rivers flowing through the body to irrigate and nourish the tissues. An obstruction in the movement of these energy rivers is like a dam that backs up the flow of water in a river. Practitioners of Chinese medicine believe these meridians conduct energy, or *Qi*, between the surface of the body and internal organs. *Qi* regulates spiritual, emotional, mental, and physical balance. *Qi* is influenced by the opposing forces of *Yin* and *Yang*. According to traditional Chinese medicine when *Yin* and *Yang* are balanced they work together with the natural flow of *Qi* to help the body achieve and maintain health. Acupuncture is believed to balance *Yin* and *Yang*, keep the normal flow of energy unblocked, and restore health to the body and mind. The principal energy pathways (meridians) are named for organs whose realms of influence are expanded from their conventional biomedical physiology to include functional, energetic, and metaphorical qualities (e.g. kidney supervises bones, marrow, joints, hearing, head hair, will, and motivation; spleen oversees digestion, blood production, blood-related functions such as menstruation, and nurturing and introspection). The meridians can be influenced by needling the acupuncture points; the acupuncture needles unblock the obstructions at the dams and reestablish the regular flow through the meridians. Acupuncture anatomy is a multilayered, interconnecting network of channels that establishes an interface between an individual's internal and external environments, permitting energy to move through the muscles and the various organs. Acupuncture treatments can therefore help the body's internal organs to correct imbalances in their digestion, absorption, and energy production activities and in the circulation of their energy through the meridians.

### **Modern Concepts**

The modern scientific explanation is that needling the acupuncture points stimulates the nervous system to release chemicals in the muscles, spinal cord, and brain (the endogenous opioid peptide system – the body's ability to produce its own pain-killing substances). These chemicals will either change the experience of pain, or they will trigger the release of other chemicals and hormones which influence the body's own internal regulating system (the neurohumoral

*Medical Acupuncture, cont. on page 10*



system). The improved energy and biochemical balance produced by acupuncture results in stimulating the body's natural healing abilities and in promoting physical and emotional well-being.

Several processes have been proposed to explain acupuncture's effects, primarily those on pain:

**Changes in brain chemistry, sensation, and involuntary body functions:** Acupuncture may alter brain chemistry by beneficially changing the release of neurotransmitters and neurohormones. Acupuncture also has been documented to affect the parts of the central nervous system related to sensation and involuntary body functions, such as immune reactions and processes whereby a person's blood pressure, blood flow, and body temperature are regulated.

**Activation of opioid systems:** Several types of opioids may be released into the central nervous system during acupuncture treatment, thereby reducing pain. Acupuncture treatment has been scientifically demonstrated to activate the endogenous opioid peptide system and thereby influence the body's pain regulatory system by changing the processing and perception of painful stimulus at various levels of the central nervous system.

**Conduction of electromagnetic signals:** There is scientific evidence that acupuncture points are strategic conductors of electromagnetic signals. Stimulating points along these pathways through acupuncture enables electromagnetic signals to be relayed at a greater rate than under normal conditions. These signals may start the flow of pain-killing biochemicals (such as endorphins) and of immune system cells to specific sites that are injured or vulnerable to disease.

By combining the neurohumoral models with other observations and speculations about the mechanism of acupuncture's impact, a hybrid model is created of an

acupuncture needle simultaneously activating multiple systems in the body's physiology: the nervous system, the blood circulation system, the lymphatic system, and the electromagnetic bio-information system. One cannot help but conceive of the human body as an electromagnetic bio-machine that can be controlled and manipulated with slight variations in bio-electrical energy inputs.

**CLINICAL STUDIES**

According to a National Institutes of Health (NIH) consensus panel of scientists, researchers, and practitioners that convened in November 1997, clinical studies have shown that acupuncture is an effective treatment for nausea caused by surgical anesthesia and cancer as well as for dental pain experienced after surgery. The panel also found that acupuncture is useful by itself or combined with conventional therapies to treat addiction, headaches, menstrual cramps, tennis elbow, fibromyalgia, myofascial pain, osteoarthritis, lower back pain, carpal tunnel syndrome, and asthma and to assist in stroke rehabilitation. Increasingly, acupuncture is used to complement conventional therapies. Doctors have found that using acupuncture lowers the need for conventional pain-killing drugs and thus reduces the risk of side effects for patients who take these drugs.

Currently, one of the main reasons Americans seek acupuncture treatment is to relieve chronic pain, especially from conditions such as arthritis or lower back disorders. Some clinical studies show that acupuncture is effective in relieving both chronic and acute or sudden pain. The National Institutes of Health have funded a variety of research projects on acupuncture that have been granted by its National Center for Complementary and Alternative Medicine (NCCAM), National Institute on Alcohol Abuse and Alcoholism, National Institute of Dental Research, National Institute of Neurological Disorders and Stroke, and National Institute on Drug Abuse.

*Medical Acupuncture, cont. on page 11*

**CONDITIONS APPROPRIATE FOR ACUPUNCTURE THERAPY**

<p><b>Digestive</b></p> <ul style="list-style-type: none"> <li>• Abdominal Pain</li> <li>• Constipation</li> <li>• Diarrhea</li> <li>• Hyperacidity</li> <li>• Indigestion</li> </ul>	<p><b>Emotional</b></p> <ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Depression</li> <li>• Insomnia</li> <li>• Nervousness</li> <li>• Neurosis</li> </ul>	<p><b>Eye-Ear-Nose-Throat</b></p> <ul style="list-style-type: none"> <li>• Cataracts</li> <li>• Gingivitis</li> <li>• Poor vision</li> <li>• Tinnitus</li> <li>• Toothache</li> </ul>	<p><b>Gynecological</b></p> <ul style="list-style-type: none"> <li>• Infertility</li> <li>• Menopausal Symptoms</li> <li>• Premenstrual Syndrome</li> </ul>
<p><b>Miscellaneous</b></p> <ul style="list-style-type: none"> <li>• Addiction Control</li> <li>• Athletic Performance</li> <li>• Blood Pressure Regulation</li> <li>• Chronic Fatigue</li> <li>• Immune System Tonification</li> <li>• Stress Reduction</li> </ul>	<p><b>Musculoskeletal</b></p> <ul style="list-style-type: none"> <li>• Arthritis</li> <li>• Back Pain</li> <li>• Muscle Cramping</li> <li>• Muscle Pain/Weakness</li> <li>• Neck Pain</li> <li>• Sciatica</li> </ul>	<p><b>Neurological</b></p> <ul style="list-style-type: none"> <li>• Headaches</li> <li>• Migraines</li> <li>• Neurogenic</li> <li>• Bladder Dysfunction</li> <li>• Parkinson's Disease</li> <li>• Postoperative Pain</li> <li>• Stroke</li> </ul>	<p><b>Respiratory</b></p> <ul style="list-style-type: none"> <li>• Asthma</li> <li>• Bronchitis</li> <li>• Common Cold</li> <li>• Sinusitis</li> <li>• Smoking Cessation</li> <li>• Tonsillitis</li> </ul>



### **WHAT IS MEDICAL ACUPUNCTURE? IS IT DIFFERENT FROM ORDINARY ACUPUNCTURE?**

Acupuncture is a very old medical art, and there are many approaches to learning and practicing it. Medical acupuncture is the term used to describe acupuncture performed by a doctor trained and licensed in Western medicine who has also had thorough training in acupuncture as a specialty practice. Such a doctor can use a combination of Western medicine and acupuncture to treat an illness. In 2000 an estimated 20,000 nationally certified acupuncturists were practicing in the United States. Currently, an estimated one-third of certified acupuncturists in the United States are medical doctors.

### **WHAT IS THE SCOPE OF MEDICAL ACUPUNCTURE?**

Medical acupuncture is a system which can influence three areas of health care: the promotion of health and wellness, the prevention of illness, and the treatment of various medical conditions. Whereas acupuncture is often associated with pain control, in the hands of a well-trained practitioner it has much broader applications. Acupuncture can be effective as the only treatment used or as the support or adjunct to other medical treatment forms in many medical and surgical disorders. The World Health Organization (WHO) recognizes the use of acupuncture in the treatment of a wide range of medical problems, including: digestive disorders; respiratory disorders; neurological and muscular disorders; urinary, menstrual, and reproductive problems; substance abuse and addiction disorder. Acupuncture is particularly useful in resolving physical problems related to tension and stress and emotional conditions.

### **WHAT ARE THE NEEDLES LIKE? DO THEY HURT?**

Acupuncture needles are metallic, solid, hair-thin, and are made from stainless steel, unlike the thicker and hollow hypodermic needles used in Western medicine to administer treatments or take blood samples. The point is smooth and insertion through the skin is not as painful as injections or blood sampling. The risk of bruising and skin irritation is less than when using a hollow needle. People experience acupuncture needling differently. Most patients feel only minimal pain as the needles are inserted; some feel no pain at all. Once the needles are in place, there is no pain felt. Some people are energized by treatment, while others feel relaxed. Physician acupuncturists carefully sterilize the needles using the same techniques as for surgical instruments, or they use disposable needles; there is therefore no risk of infection from the treatments.

The acupuncture treatment consists of inserting fine needles into the body in patterns designed to influence the flow of energy (*Qi*). Usually only one energy meridian is selected to stimulate energy movement, along with a collection of local points to focus the attention of the energy movement. Each subdivision or energy channel has a unique therapeutic point combination necessary for activation. Needles are inserted to

the depth necessary to elicit the patient's sensation of "*de-Qi*", or needle grab, a dull ache that radiates from the point. This can be 0.5 cm to 8 cm, depending on the location. The patient is positioned comfortably, usually lying supine or prone. The acupuncture needles are left in place for 5 to 20 minutes, or longer. It is crucial to protect the patient from energy depletion during an acupuncture treatment. The older or more fatigued the patient, the shorter the duration of initial treatments must be. The energy-moving needles may be stimulated when an additional activation of the acupuncture system is desired. This additional activation is accomplished through manual manipulation, by heating the needle, or by connecting the needles to an electrical stimulating device (the author's favorite technique). Focusing needles can likewise be stimulated through manual, thermal, or electrical means. It is common to treat the patient using front, back, and extremity points during the course of a single treatment session. This means that the treatment is typically divided into two sections: the energy movement section using extremity points to activate flow through the meridians and the section to focus the energy on one or several organs or to influence a pain problem.

An example of a typical medical acupuncture treatment that makes use of the traditional influences of the organs would be that of a 63 year old WM patient who complains of a general diminution of energy, including decreased sexual interest, increased sensitivity to cold weather, mild generalized joint aches, as well as ubiquitous back pain. The patient's WM is currently well controlled, and the medical evaluation and laboratory tests are essentially unremarkable. This type of presentation is extremely common in patients who have undergone cancer treatment and in patients who suffer from chronic pain (these often go hand-in-hand as many are aware). Traditional Chinese medicine would point to a manifestation of weakness in the kidney sphere of influence. An appropriate treatment plan would consist of a first section where we would activate kidney energy (and thus decrease fatigue) with properly placed needles and the use of additional focusing needles at the important points for kidney on the back ("*Ming Men*" protocol). The second section is the local treatment for the lower back pain and involves needles placed on the bladder meridian, for example at the L-2 level (somatic sympathetic for lower extremities), L-4 and L-5 levels (myotomal and dermatomal levels of pain), and at the S-2 level (parasympathetics for lower extremities) to recruit the spinal segments involved in his pain. Electrical stimulation at 4 Hz is used for 20 minutes. The local treatments for pain problems can be quite complex because, in addition to honoring the classical directive of encouraging the flow of *Qi* and blood through the channels that traverse the painful area, neuromuscular anatomy must be considered. Deliberately searching for and deactivating intramuscular trigger points in the region of pain and along the myotomal distribution



of the spinal segments involved in the pain is a necessary component of the local treatment. I use this treatment plan very often in chronic pain management.

### **HOW MANY TREATMENTS WILL I NEED?**

Patient visits are usually scheduled once weekly, although two or three visits each week are not uncommon, especially during the initial stages of an acute problem. The number of treatments needed differs from person to person. For complex or long-standing conditions, one or two treatments a week for several months may be recommended, and hopefully subsequent “maintenance” treatments can be reduced to monthly, bi-monthly, or thrice-monthly. For acute problems, fewer visits are usually required, and for health maintenance, four sessions a year may be all that is necessary. Acupuncture treatments are as individual as the patients and their responses to acupuncture. It is common to stay with an initial treatment approach for at least three or four visits before modifying the approach. If no progress has been made by the fourth visit, it is reasonable to consider including additional modalities to complement the acupuncture. One should not abandon hope that acupuncture will be of marked benefit before a full trial of 6-12 visits has been completed.

### **ARE THERE ANY SIDE EFFECTS TO THE TREATMENT?**

Usually, no side effects are encountered. As energy is redirected in the body, internal chemicals and hormones are stimulated and healing begins to take place. Occasionally the original symptoms worsen for a few days, or other general changes in appetite, sleep, bowel or urination patterns, or emotional state may be triggered. These should not cause concern, as they are simply indications that the acupuncture is starting to work. It is quite common with the first one or two treatments to have a sensation of deep relaxation or even mild disorientation immediately following the treatment. These pass within a short time, and never require anything more than a bit of rest to overcome.

### **DOES ACUPUNCTURE REALLY WORK?**

In the past 2,000 years, more people have been successfully treated with acupuncture than with all other health modalities combined. Today acupuncture is practiced widely in Asia, the Soviet Union, and in Europe. It is now being used more and more in America by patients and physicians. Acupuncture treatments can be given at the same time other techniques are being used, such as conventional Western medicine, osteopathic or chiropractic adjustments, and homeopathic or naturopathic prescriptions. It is important that your physician acupuncturist know everything that you are doing so he or she can help you get the most benefit from all your treatments.

### **DO I HAVE TO BELIEVE IN ACUPUNCTURE FOR IT TO WORK?**

No. Acupuncture is used successfully on cats, dogs, horses and other animals. These animal patients do not understand or believe in the process that helps them get better. A positive

attitude toward wellness may reinforce the effects of the treatment received, just as a negative attitude may hinder the effects of acupuncture or any other treatment. A neutral attitude (“I don’t know if I really believe in this”) will not block the treatment results.

### **ACUPUNCTURE IN CANCER TREATMENT**

Modern medicine views cancer as the result of genetic and environmental interactions which cause multiple genetic alterations (mutations) in genes. When oncogenes are inactivated, they fail to control the normal process of cell growth and death. Healthy normal cells become cancerous from a complex series of events resulting in loss of regulation of cell proliferation and programmed cell death (apoptosis). The host immune system plays an important role in the development of cancer. Immune surveillance (the recognition and elimination of cells that have undergone neoplastic transformation) is a vital function of the immune system. In effect, many believe that the development of cancer can be explained as a failure of immune surveillance.

In Traditional Chinese Medicine (TCM), uncontrolled cell proliferation and dysfunction of the immune system can be attributed to a decline or deficiency of “life essence” or *Jing* which is the substance responsible for reproduction and regeneration. *Jing* therefore exerts primary control over the processes of cellular differentiation and proliferation. *Jing* is believed to be derived from two sources: the energy inherited from one’s parents and the energy a person acquires in his or her daily life (chiefly from air, food and water). *Jing* also works with *Qi* to help protect the body from harmful external factors. *Jing* and *Qi* have a close relationship in traditional Chinese medicine, and are believed to form the foundation for the *Shen*, or spirit. *Jing* is stored in the kidneys and also determines basic constitutional strength and resistance to exterior pathogenic factors. *Jing* is the basis of marrow, which produces the common matrix of bone marrow, brain, and spinal cord. Thus, *Jing* has an important role in maintaining proper immune function by producing bone marrow that contains the pluripotent stem cells that give rise to immune cells. The differentiation of stem cells and subsequent proliferation of immune effector cells are also governed by *Jing* – a decline or deficiency could result in an individual’s immune system failing to recognize and eliminate cells that have undergone neoplastic transformation.

The use of acupuncture in oncology for management of treatment-related adverse effects and for palliative care is finding greater acceptance in Western medicine. Although the evidence is not extensive and randomized controlled trials are lacking, acupuncture appears to be of benefit for: managing chemotherapy-induced nausea and vomiting; cancer-related pain; generalized symptoms that result from treatment such as fatigue, insomnia, diarrhea, and anorexia; radiotherapy-induced xerostomia (decreased saliva); nerve damage



from lymph node resection for breast cancer; treatment-related vasomotor symptoms; radiotherapy-induced rectal inflammation and irritation; and end-of-life symptoms such as dyspnea (shortness of breath).

The efficacy of acupuncture for relief of treatment-related adverse effects and palliative care of cancer patients has been investigated most extensively for management of chemotherapy-induced nausea and vomiting and cancer-related pain. The impact of acupuncture on immune function and treatment-induced myelosuppression (decreased level of red cells, white cells, and platelets in the bone marrow) has also received considerable attention. A number of exciting studies have suggested that acupuncture can enhance immune function and be effective for treatment of chemotherapy- or radiotherapy-induced myelosuppression.

A randomized study of 76 cancer patients assessed the impact of acupuncture on leukocytopenia (low number of white cells in the blood) and thrombocytopenia (low number of platelets in the blood) resulting from chemotherapy or radiotherapy. Following 30 days of cancer treatment, there was a significant 35% decline in leukocyte count and an 18% (non-significant) decline in platelet count in the non-acupuncture treated group, while in the acupuncture group there was no change in the leukocyte count and a significant 17% increase in the platelet count. In other studies, patients with chemotherapy-induced leukocytopenia experienced significant increases in the leukocyte count compared to non-acupuncture treated cancer patients. One clinical study reported that during chemotherapy, patients receiving daily acupuncture treatments of 15-30 minutes for 7 days had significantly higher leukocyte counts than patients in a control group. In a 2nd clinical series, daily treatment for 10-30 days was also reported to elevate the decreased hemoglobin levels and leukocyte and platelet counts caused by chemotherapy. Despite many studies and encouraging results, more stringent trials need to be performed to fully evaluate acupuncture's role in cancer-related leukopenia.

Several investigators have shown that acupuncture enhances various parameters of cell-mediated immunity in patients with cancer who exhibit immunosuppression: significant increases in CD3+ and CD4+ T-lymphocyte subgroups and an elevated CD4+/CD8+ ratio following 10 daily treatments

of 30 minutes each were noted. In a study of similar design, 10 daily treatments of 30 minutes each elevated the level of interleukin 2, which induces the proliferation of T-cells and increased NK cell activity. Future clinical studies of acupuncture as an adjunct to monoclonal antibody therapy would only seem to be a logical extension to these exciting findings. Rituximab and acupuncture anyone?

Acupuncture used successfully for the non-pharmacologic approach to treating patients with shingles (herpes zoster) compared favorably with standard antiviral drug therapy in a preliminary study.

Peripheral neuropathy is a vexing symptom for many WM patients. Acupuncture has been used with mixed success in this setting. Peripheral neuropathy remains a very difficult condition to treat in the best of settings, and one cannot say with any certainty that acupuncture will be of benefit to all who suffer from PN. A recent article in the 2007 *European Journal of Neurology* did suggest, however, that acupuncture treatment improves nerve conduction in peripheral neuropathy in some patients. More importantly, perhaps, subjective improvement was noted along with improvement in nerve conduction in those patients suffering from idiopathic PN

Interest in the use of acupuncture and evidence documenting its efficacy for treating cancer-related symptoms and therapy-induced adverse effects have increased steadily during the past few decades. As part of an effort to encourage further research that has the potential to improve the quality of life for individuals with cancer and/or HIV/AIDS, the National Center for Complementary and Alternative Medicine has provided funding for research in acupuncture. Ongoing research continues to further our knowledge of the benefits of acupuncture for individuals with cancer.

**FOR MORE INFORMATION:**

The NIH National Library of Medicine (NLM) has published a bibliography of more than 2,000 citations to studies conducted on acupuncture: [www.nlm.nih.gov/pubs/cbm/acupuncture.html](http://www.nlm.nih.gov/pubs/cbm/acupuncture.html)

The NLM also has a toll-free telephone number: 1-888-346-3056. For a database of research on complementary and alternative medicine, including acupuncture, access the CAM Citation Index on the NCCAM Web site at: [www.altmed.od.nih.gov/nccam](http://www.altmed.od.nih.gov/nccam)



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# WALDENSTROM'S MACROGLOBULINEMIA AND THE SKIN

BY JULIA S. LEHMAN, M.D.

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Waldenstrom's macroglobulinemia (WM) involves excessive production of a particular protein called immunoglobulin M (IgM). Although the most common symptoms of WM include



Dr. Julia S. Lehman

tiredness, weakness, weight loss, and bleeding of the nose or gums, some patients may develop skin rashes.

Such rashes may develop from direct infiltration of the skin by cancerous blood cells (lymphoplasmacytoid B cells). In these cases, patients can develop non-specific reddish-brown to purple patches or plaques (flat-topped, raised patches) on their skin. A very rare phenomenon related to WM that may affect the skin is a

condition called "Schnitzler Syndrome." Patients with this condition develop hives (urticaria) in association with fever and bone pain.

More commonly, patients with WM will develop skin lesions as a consequence of excess blood proteins sludging in the blood vessels. Because skin blood vessels near the toes, fingers, and ears are among the smallest vessels, and therefore the most likely to get plugged, these areas are most frequently affected. At these sites, patients may get purplish change of the skin (purpura), which may be painful if the associated small blood vessel occlusion reduces blood supply to these locations. Sometimes, patients will develop net-like purple skin lesions (livedo reticularis), which represents low blood flow to the areas between larger blood vessels in the skin. Uncommonly, the skin can break down over these skin changes, leading to skin erosions and ulcers.

Because people with WM have impaired immunity, they are at higher risk for certain types of infections. A common infection associated with rash that may affect patients with WM is shingles (caused by reactivation of the chicken pox virus). Shingles, or herpes zoster, is characterized by the appearance of clustered blisters, usually confined to a single area of the body, which can be itchy or painful. The best

treatment for shingles, antiviral medications, is most effective if it is started early in the disease course. Unfortunately, shingles may leave patients with long-lasting discomfort at the site of involvement, even if the original rash has subsided. Some medications, both topical and oral, may be helpful in alleviating this discomfort.

Another non-specific infection that may occur in patients with WM is cellulitis. When bacteria enter through breaks in the skin and cause cellulitis, patients may experience fever and pain, swelling, and expanding redness at the site of involvement.

Finally, the chemotherapy medications used to treat WM can cause a variety of rashes. The most common chemotherapy-related rashes include painful red bumps on the palms (neutrophilic eccrine hidradenitis), which is not usually intrinsically serious but may be bothersome to patients. Loss of hair is another common and expected cutaneous side-effect of certain chemotherapeutic agents.

If you or someone you know with WM develops a rash that is painful, purple, or associated with fevers, chills, or feeling ill, a doctor should be consulted immediately.

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# A PILGRIM'S PROGRESS TOWARD HEALING

BY MARINA SKULSKY, M.D.

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*Marina Skulsky is a family physician in Calgary, Canada, and wife of the late Dr. Blythe Brown, a Waldenström's patient. Dr. Skulsky here recounts how she honored her late husband by hiking the road to Santiago de Compostela in Spain.*

Everyone takes the pilgrims' road to Santiago de Compostela for different reasons – religious struggles, self-discovery,



*Modern-day pilgrim Dr. Marina Skulsky stands proudly at kilometre zero in Obradoiros Square at the end of her 165-kilometre walk in memory of her husband.*

beautiful scenery and physical challenge. Mine was to walk away grief. There are granite markers along the trail engraved with scallop shells that tell you the number of kilometres to Santiago. I encounter my first at kilometre 155. I put a small piece of white quartz on top of it to commemorate my journey, just as many before me had done.

My mantra as I set a stone on each marker became: “Blythe, my darling, I love you, rest in peace.”

Traveling together has always been an important part of our family. So when my husband, Blythe Brown, a frequent *Medical Post* writer and Calgary family physician, died on March 21, I wanted to honour him in the best way I knew how. We had traveled and written about many places, but one special place was left undone. We had always planned to walk the French Camino into Santiago de Compostela (St. James of the Field of Stars) in northwest Spain. We had planned to go a year after rehabilitating from his bone marrow transplant. Tragically, our trip together wasn't meant to be.

While preparing his eulogy, I came across two letters he'd written encouraging me to organize this trip; either together or alone, if need be. After 33 years of marriage, who was I to argue? With less than a week of planning and two weeks after his funeral, I traveled with trepidation to northern Spain to do my 165-kilometre memorial walk.

There are many ancient pilgrim roads (caminos) throughout Europe that lead to Santiago, but the most frequented today, and in the past, is the French Camino, which crosses into Spain through a pass in the Pyrenees. I started my journey from the city of Leon, about halfway along the French Camino.

Santiago was St. James the Great, one of the 12 apostles. Legend has it that he was taken back to northern Galicia to be buried with the people he converted to Christianity.

Beheaded by the Roman emperor Agrippa I, he became the first Christian martyr, which enhanced his importance.

## Early Travel Guides

The first complete pilgrim's travel guide was done in the year 1135, the *Codex Calixtinus* by the French cleric, Aymeric Picaud. Indeed, in the Middle Ages, there were 300,000 pilgrims (pelgrinos) a year trudging to Santiago. This required the complex development of hospitals, hostels and safe passage for all medieval travelers. Each pilgrim wore a wide brimmed hat, carried a walking staff, toted a gourd for water and wore a long cape with a scallop shell – their insignia as a pilgrim. The scallop allowed safe passage and penalties were harsh should a pilgrim meet with foul play.

Fast forward to 2009. I arrived in Bilbo, in northern Spain and took a five-hour train trip to Leon, and I was ready to begin. Traveling alone, I thought it was best to access some services to support my trek. Normally a detail-oriented person, I was doing this strictly on faith that things would fall into place. Nonetheless, I happened upon an excellent local Spanish tour company online called Fresco Tours ([www.frescotours.com](http://www.frescotours.com)). Alex and staff travel the French Camino every two weeks from April until October. He couldn't have been kinder or more supportive of my quest. They arranged hotels, luggage transfers, and meals.

I was charged with carrying my daypack, map, my pilgrim passport and finding my pace on the Camino. Many others backpacked and stayed in hostels or homes on the way. Almost immediately, I could feel the Camino spirit. Anyone passing you on foot or bicycle would call out, “Ola! Buon camino!” (Hello and good journey!) That became your first greeting with each fellow traveler encountered no matter their language or country.

There is something very special about following a 1,200-year-old path that millions of people have traveled before you. In solidarity, all footsteps in the dust point in the same direction. The stone and paths are worn in gracious anticipation of providing something greater than oneself. It is a solitary endeavour as everyone walks at his own pace.

The first five kilometres are up a mountain to O Cebreiro. It snowed the day before I climbed in early April. The weather is extremely changeable – just like the Rockies! But I was grateful for cool, clear, beautiful skies and light winds. The lime green forests and fields were punctuated by small areas of snow as I climbed. There was a misty rain and thick fog at the top that added to the mystery of my journey into the unknown.

At O Cebreiro, members of the Fresco Tours regrouped for dinner (seven of us) and shared a meal cooked by Pilar, whose

*A Pilgrim's Progress, cont. on page 16*



family has cooked for generations of pilgrims. It was cozy in the restaurant, but there was little heat in my stone room and I longed for a familiar body to warm up to. Socks and my fleece vest would have to suffice.

This tiny five-house, one-church, hamlet is steeped in history and miracles. There are pallozas (pre-Roman stone dwellings) here that were first documented as a traveler's hostel in the year 836. In the 1200s, a faithless monk celebrating mass secretly berated a peasant who bravely climbed the mountain in a snowstorm to attend the service. At the moment the monk elevated the Host, it turned into blood and flesh and stained the white linens. Today the Chalice and clothes are venerated as part of the archeological relics in this tiny church. In fact, King Ferdinand and Queen Isabella made the pilgrimage here in 1486 – six years before the discovery of America!

My pilgrimage started in earnest the next morning. For 10 days I journeyed between 25 and 30 kilometres per day, nursing blisters with moleskin and finding solace in the challenge of each new spring day. I passed through lovely little towns and ruins with romantic names such as Tricastela (three castles), Portomarin (door to the sea) and Palas de Reis (Palace of the Kings). I stopped at Samos, the oldest monastery in Spain, to hear the monks sing vespers in the evening. The singing warmed my spirit and the local spinach bean soup warmed my body. No meal is complete unless you are offered the Tarte de Santiago. This almond torte is topped with the distinctive medieval sword of St. James formed in an icing sugar imprint. All pilgrims are charged with finding the best torte on the camino.

Thus the camino takes on its own rhythm – sore joints, camaraderie, commiseration, humour and peace. I walked in silence on the worn stone and country lanes, crossing sheep herds and dodging cow patties. I listened to the birds and felt the misty rain, braced against cold mountain winds, crossed the streams. Only one day did I feel particularly alone in a dark part of the forest. The very next marker answered me. “You never walk alone” was etched on it. It affirmed my belief that Blythe was encouraging me along on this camino. I felt the pouch in my pack that carried a bit of clay from his grave and a polished piece of British Columbia jade, a keepsake from his family, and walked on, comforted.

As one goes on, you can feel and see the dogged persistence of previous pilgrims. There are the dilapidated hiking boots held together by duct tape as heels and soles are worn through. Eventually they are discarded atop a camino marker. As you go through each town you get a stamp in your pilgrim passport. This is your cherished document. It is proof that you walked at least the last 100 kilometres to Compostela and you receive a certificate from the church.

A palpable anticipation increases in all peligrinos as one gets closer to Santiago. On a clear day, jubilant pilgrims would race to the summit of Monte de Gozo to become “King of the Pilgrimage.” The first to see the spires of the cathedral a few kilometres away obtained this honour.

### **Kilometre Zero**

Entering Santiago, I followed the bronze scallops imbedded in the walkways. All bring you down the narrow roadways that suddenly open to Obradoiros Square where a bronze plaque marks kilometre zero. Accompanying this was the outpouring of laughter, hugs and tears as everyone threw up their arms in relief as they stood on the marker in front of the 1,000-year-old church. At noon the following day, a pilgrims' mass was celebrated. The special Pilgrims Blessing was given and the pilgrims' countries' names were read out. It was a tired, motley group of individuals who joyfully embraced. They came from a multitude of countries, the scallop shell their common flag.

At that moment, there is faith and hope for peace in the world that transcends all religions and boundaries. The end of the service almost marked the end of my personal pilgrimage. There was relief and joy, peace and sorrow, loneliness and solace. I know Blythe would have loved this walk with his usual unbridled enthusiasm. His humour and joie de vivre would have brought a whole new dimension to this trip. So I counted my blessings and enjoyed the memories...

But before I left the cathedral, I had a task to perform. Out from the bottom of my pack came the little bit of clay from Blythe's grave and the polished jade rock. I found a tiny crevice in a stone at the far back of the 1,000-year-old altar and deposited my treasures. Blythe, my darling, we've arrived!

*From The Medical Post of July 21, 2009, this article is printed in the Torch by permission of the author.*



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# MEDICAL NEWS ROUNDUP

BY SUE HERMS

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**Results Announced for Single Agent Arzerra in Both NHL and CLL** – GlaxoSmithKline and Genmab announced results from a study of single agent Arzerra (ofatumumab) in follicular lymphoma patients who were highly refractory (resistant) to rituximab. Arzerra is a “new generation” anti-CD20 antibody that binds to a different part of the CD20 surface marker on B-cells than does rituximab. The initial study used two dosages, 500 mg and 1000 mg, but the study protocol was amended to discontinue 500 mg dosing. The overall response rate was 10% in patients receiving the higher dose of 1000 mg, with 50% of patients having stable disease. There were no unexpected safety findings, the most common adverse effects being rash, hives, itching, fatigue, nausea, fever, and cough. Most observers feel that these results were disappointing and that Genmab executives had hoped for a response rate of at least 25%. The data may affect the drug’s prospects for NHL treatment as a single agent, although the company has recently received accelerated approval of Arzerra in patients with chronic lymphocytic leukemia who are refractory to fludarabine and alemtuzumab (Campath). Some observers believe that in order for Arzerra to be approved for single agent therapy in NHL it will need to initiate head-to-head trials with rituximab.

**Combination Arzerra with CHOP Yields Encouraging Results in Follicular Lymphoma** – Meanwhile, a Phase II trial of Arzerra combined with CHOP (cyclophosphamide, doxorubicin, vincristine, and prednisone) for the treatment of follicular lymphoma yielded an overall response rate of 90% at a 500 mg dosage and a response rate of 100% at a 1000 mg dosage of Arzerra.

**FDA Clarifies Process for Patients Who Seek Access to Investigational Drugs** – Seriously ill patients who lack good treatment options sometimes want to try a promising drug that is still under development. These patients hope the drug will provide them with a lifeline where none previously existed. Because of this need, the U.S. Food & Drug Administration (FDA) recently issued two rules that seek to clarify the process available to seriously ill patients interested in gaining access to investigational drugs when they are not eligible to participate in a clinical trial and do not have other satisfactory treatment options. The agency is also clarifying the specific circumstances and the types of costs for which a manufacturer can charge patients for an investigational drug used either as part of a clinical trial or outside the scope of a clinical trial. The new FDA website with this information for both patients and doctors is located at [www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/AccessToInvestigationalDrugs/default.htm](http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/AccessToInvestigationalDrugs/default.htm).

**Aerobic Exercise Improves Quality of Life for Lymphoma Patients** – A joint Canadian-United Kingdom study conducted between 2005 and 2008 investigated the effects

of aerobic exercise on the physical functioning and quality of life of lymphoma patients. Twelve weeks of aerobic exercise significantly improved physical functioning, cardiovascular fitness, and overall quality of life without interfering with chemotherapy completion rate or treatment response. The researchers suggest that exercise training to improve cardiovascular fitness should be considered in the management of lymphoma patients.

**Phase III Study Reports Results for Maintenance Rituximab in Follicular Lymphoma** – Genentech reported a Phase III multi-center study on patients with follicular lymphoma who continued to receive maintenance rituximab once every two months for two years after responding to combination chemotherapy and rituximab. The study showed that these patients lived longer without their disease worsening (progression-free survival) than those who did not continue to receive rituximab. The study was sponsored by Groupe d’Études de Lymphomes de l’Adulte. Genentech will discuss the next steps for this potential new indication for rituximab with the FDA and with European regulatory agencies.

**Swiss Group to Investigate 5-Year Rituximab Maintenance** – So far, most studies of maintenance rituximab have limited maintenance duration to 2 years. The Swiss Group for Clinical and Epidemiological Cancer Research is currently investigating the efficacy and toxicity of rituximab maintenance for 5 years in follicular lymphoma. This study should reveal whether prolonged rituximab maintenance will lead to prolonged progression free survival, whether there will be a percentage of patients developing rituximab resistance, and whether long-term maintenance will lead to decreasing immunoglobulin serum levels and subsequent immunodeficiency.

**Treatment Location Can Affect Survival of Lymphoma Patients** – A study reported by the Nebraska Medical Center in Omaha suggests that lymphoma patients’ survival can depend on where they live and where they get treated. Low- to intermediate-risk patients living in rural areas were up to 37% more likely to die if they received care at a community-based center rather than a university-based treatment provider. For patients with high-risk lymphoma, urban residents treated at urban, university-based centers also survived longer than rural residents. Patients treated at community-based centers were less likely than those treated at university-based centers to receive cutting edge treatments such as stem cell transplants. The study’s authors believe that better care coordination could go a long way toward improving outcomes for rural patients, while patients themselves need to take responsibility for asking about new treatments and making sure they get the appropriate follow-up care. Strategies such as telemedicine

*Medical News Roundup, cont. on page 18*



could be more widely utilized to help improve care of rural residents.

**Dana-Farber Tests Src Inhibitors on WM Cell Lines and Patient Samples** – Src tyrosine kinase is a protein which regulates cell proliferation, migration, adhesion, and survival in tumor cells and is over-expressed in WM cells. The Dana-Farber Cancer Institute has tested a specific Src tyrosine kinase inhibitor, called AXD0530, on WM cell lines and patient samples. Although this drug led to significant inhibition of Src tyrosine kinase and induced cell cycle arrest, it had minimal effect on the survival of WM cells. However, it may be possible to test Src inhibitors in combination with other drugs to improve the outcome for WM patients.

**Innovative Computer Software Developed to Discover Genetic Mutations Leading to Cancer** – Engineers at the Johns Hopkins University have devised innovative computer software that can sift through hundreds of genetic mutations and highlight the DNA changes that are most likely to promote cancer. The new process focuses on missense mutations, meaning protein sequences that each possess a single tiny variation from the normal pattern. A small percentage of these genetic errors can reduce the activity of proteins which suppress tumors or hyperactivate proteins that make it easier for tumors to grow. The new computational method is called CHASM, short for Cancer-specific High-throughput Annotation of Somatic Mutations. So far, this method has been tested using brain cancer DNA, with the results published in the journal *Cancer Research*. The software developers plan to post their system on the Internet to allow researchers worldwide to use it freely for their studies.

**St. Jude Children’s Research Hospital Highlights TEL2 Gene in the Development of B-Cell Lymphoma** – St. Jude Children’s Research Hospital researchers have highlighted the role of a gene called TEL2 in the development of pediatric B-cell lymphomas. TEL2 does not cause cancer directly. Instead, it cooperates with the MYC gene in promoting the development of lymphoma by enlarging the B-cell population. This increases the likelihood that a few of the cells will acquire a mutation that inactivates the function of p53, a gene that normally orchestrates the ability of abnormal B-cells to undergo apoptosis (death). The study’s findings suggest that physicians should look for TEL2 activity as part of the diagnosis of B-cell lymphoma and that it should be considered a potential target for novel drugs to treat the disease.

**The Cancer Genome Atlas Hopes to Improve Cancer Diagnosis, Treatment, and Outcomes** – President Obama announced additional funding of \$175 million toward a large-scale collaborative effort by the National Cancer Institute and the National Human Genome Research Institute to systematically characterize the gene changes that occur in cancer. The goal of this project is to collect more than 20,000 tissue samples from more than 20 cancers and involves over

150 scientists at dozens of institutions around the U.S. It is hoped that The Cancer Genome Atlas (TCGA) will fuel rapid advances in cancer research, including new ways to categorize tumors, new therapeutic targets, and methods that will allow clinical trials to focus on patients who are most likely to respond to specific treatments. All data will be rapidly deposited in databases accessible to the worldwide research community.

**Umbilical Cord Stem Cell Product Called StemEx to Be Tested in Phase III Multi-Center Study** – Gamida Cell has announced a multi-center study to enroll patients in the StemEx research study. This is a Phase III trial assessing the safety and efficacy of StemEx, an investigational product derived from stem cells, as an alternative treatment to bone marrow transplants for hematological malignancies including leukemia and lymphoma. StemEx is a graft of expanded stem cells taken from a single unit of umbilical cord blood and then transplanted in combination with non-expanded cells from the same unit. Previous research has shown that umbilical cord blood stem cells offer a viable option for leukemia and lymphoma patients without the necessity of a matched donor. StemEx has orphan drug designation in the U.S. and Europe.

**Increased Incidence of NHL Associated with Diabetes** – The Tufts University School of Medicine is reporting that an analysis of several studies from 1997 and later shows a moderately increased incidence of non-Hodgkin’s lymphoma (NHL) in patients with diabetes. The risk ratio was calculated as 1.19. The team noted that since diabetes is characterized by immune dysfunction related to impaired neutrophil activity and changes in immunity, this may account for the increased risk of NHL.

**Japanese Study Discusses Rituximab Resistance and Possible Method to Reverse Resistance** – The Nagoya University Graduate School of Medicine in Japan observed that resistance to rituximab has emerged as a considerable problem as the drug has become more widely used to treat B-cell lymphomas. Over the past five years, several groups have reported a CD20 negative change in CD20 positive lymphomas after rituximab treatment. This Japanese study found that CD20 negative transformation developed in approximately 26% of patients who were previously treated with combination therapy including rituximab and whose disease had relapsed. It was also concluded that patients with CD20 negative relapsing disease tended to have a shorter survival time than patients with CD20 positive relapsing disease. The researchers suggested a larger study to confirm these observations. They also reported that a DNA methyltransferase inhibitor such as 5-Aza was able to partially restore rituximab sensitivity in cell cultures of relapsed CD20 negative patients, thus presenting a possible salvage strategy in such patients.



**Results Announced for Pixantrone in Studies of NHL** – Cell Therapeutics Inc. announced highlights of its pixantrone Phase II and Phase III clinical studies in relapsed/refractory aggressive and indolent NHL patients. When pixantrone was used in combination with fludarabine and rituximab, the complete response rate was 70% in indolent lymphoma. When combined with cyclophosphamide, vincristine, and prednisone, the complete response rate was 47% in aggressive lymphoma, and when combined with rituximab only, the complete response rate was 35% in indolent lymphoma. The most common side effects were neutropenia, leukopenia, infection, anemia, thrombocytopenia, fever, weakness, and cough. Pixantrone is in the same general class as doxorubicin but without the severe side effect of heart toxicity.

**New Combination Therapy Developed for Treatment Prior to Autologous Transplantation** – There is great interest in chemotherapies for relapsed or refractory lymphomas that are both directly effective against the lymphoma and able to mobilize peripheral blood stem cells for rescue after high-dose chemotherapy. Patients at the Universita di Pavia in Italy were treated with a regimen called MJMA (mitoxantrone, carboplatin, methylprednisolone, and cytarabine) for a median of five cycles. Approximately 68% of these patients had complete responses to treatment and were able to mobilize stem cells for subsequent autologous transplantation.

**Joint Canadian-U.S. Study Reports on Bendamustine (TREANDA)** – A Canadian-U.S. multi-center study of single agent bendamustine hydrochloride (TREANDA) reported an overall response rate of 75% in patients with rituximab-refractory, indolent B-cell lymphoma. Notably, 14% of patients achieved a complete disappearance of clinical evidence of their disease. Patients received an intravenous dose of 120 mg/m<sup>2</sup> on days 1 and 2 every 21 days for 6-8 cycles. Toxicities included neutropenia, thrombocytopenia, anemia, nausea, infection, fatigue, diarrhea, vomiting, fever, constipation, and loss of appetite.

**FDA Approves Zevalin As Front-Line Treatment for NHL** – The FDA recently approved the radioimmunotherapy drug Zevalin as a front-line treatment for non-Hodgkin's lymphoma. Previously, the drug was approved only to treat

lymphoma after a relapse or after all conventional therapies failed.

**Monoclonal Antibody Ipilimumab Tested in B-Cell Lymphoma** – A study in *Clinical Cancer Research* reported on a monoclonal antibody called ipilimumab in a Phase I clinical trial in patients with relapsed/refractory B-cell lymphoma. This antibody, which blocks cytotoxic T-lymphocyte antigen 4 (CTLA-4), improves host resistance to tumors by increasing T-cell proliferation. Thirty one percent of patients had significantly increased T-cells following this dose escalation and safety trial. The most common side effects were diarrhea, headache, abdominal pain, loss of appetite, fatigue, neutropenia, and thrombocytopenia. Further studies of ipilimumab alone or in combination with other agents are recommended.

**New Combination Treatment Regimen Reported for MM and WM Patients Who Cannot Tolerate Steroids** – A recent Phase II clinical trial published in *Leukemia and Lymphoma* discussed treatment of patients with recurring multiple myeloma, plasma cell leukemia, or WM with a steroid-free regimen of bortezomib (Velcade), doxorubicin liposomal (Doxil), and thalidomide (Thalomid). Scientists at the State University of New York who performed this trial were looking for a successful therapy for patients who cannot tolerate steroids. Ten out of 23 patients reached partial or complete response; five of the remaining patients had minimal response or reached stable disease. Toxicities included thrombocytopenia, neutropenia, mild neuropathy, and moderate fatigue.

**Atacicept Tested in Multiple Myeloma and WM Patients** – A Phase I European clinical trial, sponsored by ZymoGenetics Inc., tested a subcutaneous therapy called atacicept on 16 multiple myeloma and WM patients with advanced disease. Atacicept is a protein that binds to and neutralizes the B-cell survival factors BLYS and APRIL. The drug was well tolerated. Three of the four WM patients in this trial were progression-free after the first cycle.

*The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Daniel Hachigian, John Paasch, Colin Perrott, Howard Prestwich, and Bert Visheau in disseminating news of interest to the IWMF-Talk community.*



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# FROM IWMF-TALK

BY MITCH ORFUSS

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IWMF TALK had a very lively autumn season. Quite a wide range of topics was on the minds and fingertips of TALK readers and, once again, what follows is a fecund sampling of a dozen topics.

## Insurance Status of PET and CT Scans

If coverage of a PET scan is denied, **Howard Prestwich** suggests we read our whole policy in advance of further action and look at the language used to deny the claim, then read it again and again...look at the denial letter for why the claim was turned down...review what the submitting doctor has submitted to date about why she ordered the PET scan... was she looking for other cancers, trying to find out how advanced the WM was? Both?

**Daniel Hachig** wrote that he was covered by Anthem/Blue Cross California when his Martina had her PET scan at Stanford. The pre-approval for the scan was denied, so Stanford resubmitted using lymphoplasmacytic lymphoma as the diagnosis. It was then approved...so if the billing office hasn't already tried, Howard strongly suggests resubmitting a diagnosis of LPL.

**Garry Francell** went to M.D. Anderson in Houston because no one in his home state of Hawaii seemed to know what to do with WM. He had a PET scan in Hawaii and another at Anderson – Blue Cross paid for both.

**Bob Reeber** said that both Medicare and BCBS paid for his scans. He has had several over the past nine years. The first one followed pneumonia and identified a foreign lump in his lung. The lump eventually disappeared with Rituxan treatment as shown by a second CT scan. His pulmonologist recently ordered a second chest CT scan to check on the bronchiectasis that resulted from immune system weakness brought on by WM.

Sometimes applicants need prior approval and the doctor's office should be aware of when this is the case. **Cathy Thompson** described how she'd just found out that her insurance wouldn't pay for a PET scan. The bill is \$5,000.00. Cathy tried twice to appeal – both appeals denied. Her doctor's billing office reported that Blue Cross would not pay. Cathy has been with Blue Cross for years and they had never before denied a claim. This time they said the scan was “not

medically necessary.” Wouldn't any test an oncologist orders be necessary? Cathy then asked for advice on how to win her case. The billing office told her that an insurance company may deny a claim as far into the future as two years.

## Pluses and Minuses of Various Treatment Options

Dennis Grandcolas asked about Velcade. Dennis' initial question about Velcade was prompted by an e-mail exchange that he had with a Dana-Farber doctor who suggested that possibly adding Velcade to his 88-year-old mother's Rituxan treatment (currently one Rituxan treatment per month) could be helpful. When Dennis suggested this to his mother's oncologist, he was told that Velcade was not available for WM patients. Seems like there is some gray area here that several on IWMF-TALK have addressed. Dennis' mother is a cause for concern in that she struggles with how she feels during the course of treatment. Her complaints include the expected low-grade fever, night sweats, general bad feeling. But her side effects seem more severe than most, to the point that she considers treatment cessation. Dennis thought the suggestion of Velcade might potentially lead to better results but admits he doesn't know since it was just a suggestion from a prominent doctor based only on an e-mail exchange.

**Gerry Wergland** said that another TALK response, from **Sue Herms**, reflected the latest clinical trial information, particularly the dosing schedule to reduce the risk of peripheral neuropathy (PN). There was an earlier trial run at Dana-Farber with a twice weekly dosing of Velcade that resulted in higher rates of PN. Gerry completed seven cycles earlier this year and continues on Rituxan maintenance. Gerry had very good response, with IgM falling from over 5,000 to 250. However, Gerry agreed with Sue's point about exercising caution in treating older patients. Gerry has found that Medicare pays for Velcade and Rituxan; he says it helps to have good Medicare supplement coverage (“Medigap”) as the treatment is expensive and coverage under Part B Medicare is only 80%.

## Cold-Induced Hives

**Sandra Proctor** writes that cold-induced hives were her first symptom before diagnosis. When diagnosed with WM in 2000, Sandra was also tested for, and was positive for, cold

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



agglutinin disease. **Amy Deraghy** wrote that she doesn't know how common cold-induced hives are but suggests that they can be associated with WM. Amy spoke to people at the Ed Forum last spring who also had "c-i" hives. The hives were, in fact, the reason she was diagnosed with WM. She'd started getting them on her morning bike commute and saw an allergist who was immediately suspicious and found that Amy's IgM was elevated and so sent her to an oncologist/hematologist – bingo! So far Amy has tested negative for cryoglobulinemia and cold agglutinin disease. Her hives are well controlled with antihistamines. She takes fexofenadine daily. If she knows she'll be out in the cold more than usual, she also takes loratadine or cetirizine the night before.

**Eileen Sullivan** thought it interesting to describe cold-induced hives as a WM-related symptom. Eileen had developed that problem two years ago, well after her transplant and complete remission. Eileen's transplant doctor said it was not a typical transplant reaction but that strange things sometimes happen. So she had not connected it with WM at all. Eileen also has occasional pressure-related hives and has tested negative for cryoglobulinemia.

#### **Rituxan Considerations**

**Fay Langer** wrote that Bloomberg reported a third patient on Roche's Rituxan developed a rare and potentially fatal brain disease. The sufferer was an arthritis patient. **Dr. Tom Hoffman** replied that Fay was talking about PML and said that there was nothing new here. This is a known complication and more than 60 cases have been reported in the last ten or twelve years. In fact, this is the first complication noted in the package insert. All doctors will say that chemo has serious side effects that can kill. However, more people will benefit from chemotherapeutics than be harmed by them. Otherwise, says Dr. Tom, nobody would be taking chemo.

**Dr. Guy Sherwood** writes: "As long as one continues to receive rituximab, we will continue to see effects such as hypogammaglobulinemia (low IgG, IgA, and of course - hopefully - low IgM). Rituximab attacks healthy CD-20 B-cells as well and therefore reduces "healthy" production of immunoglobulins. This is why we have the dreaded PML. Rituxan is not without side effects. Furthermore, it appears that some WM patients also have a coexisting illness called "common variable immunodeficiency syndrome," or words to that effect, which causes hypogammaglobulinemia. Nothing can be done for this – apart from IVIG infusions – that I am aware of."

#### **First-Time Treatment Decisions**

**Bobbie Jean Dabney** writes that her WM progressed after 12 years of WM on wait and watch with only Procrit injections every 3 weeks for anemia. Her oncologist just did a new complete work-up to re-stage the disease and the CT scan shows a mass in the left lung. A bronchoscopy revealed low grade B-cell lymphoma involving the lung. So, the doctor said, it's time to treat. Her options are Rituxan/Velcade,

Rituxan/Cytoxan/cladribine (2CdA), or Rituxan/Cytoxan/dexamethasone. Bobbie has mentally decided against Velcade because of the PN possibility and is asking anyone who has had either of the other two to detail the pros or cons of their experiences. She senses that her oncologist favors the 2CdA combo, but Bobbie is concerned about the possibility of transformation.

**Alice Riginos** replied that she'd been treated successfully in summer 2008 with 5 rounds of DRC – dexamethasone, Rituxan, and Cytoxan. From IgM 7040 and HgB 10.2, her most recent numbers are IgM 2070 and HgB 14.2. She had difficulty with neutropenia and lost a lot of hair (but not all). Some nausea as well. Previously Alice had Rituxan x 4 in both 2003 and 2005. A minor response followed both treatments with IgM never falling below 4800 (down from 9000 and 9900) and hemoglobin rising as high as 12. She is entirely satisfied that her excellent Mayo Clinic specialist advised "treating the symptoms and not the numbers" for the 5 years that she had IgM hovering around 5000 but, apart from anemia, remained asymptomatic. She feels that minimal use of Rituxan was a prudent course of treatment for those years. Alice is certainly pleased, however, with her new numbers that resulted from the more toxic DRC treatment and is hopeful that this response will be more durable than the previous two with solo Rituxan.

**Renee Paley Bain** suggested that Bobbie not rule out 2CdA. The risk of transformation is low and the nucleoside analogs as a class of drugs have been very effective against WM, particularly in combination with Rituxan. **Dr. Tom Hoffman** then offered that, when talking about 2CdA, we should factor in the permanent bone-marrow suppression that it can also cause.

**Daniel Hachig** writes: "Whether the combined risk of MDS/transformation as a result of the purine nucleosides can be considered 'low' is a matter of considerable debate. Dr. Treon's retrospective study of 439 patients pegged the rate of MDS at 1.6% and transformation rate at 4.7%. There are 3 French studies (1 prospective, 2 retrospective) showing MDS at 1.4%, 6%, and 8.9% with transformation risk at 6.6%, 7%, and 8%. Down in Australia, Dr. Seymour found the rate of MDS to be 11.6% but less than 5% in previously untreated patients. The good news (if you will) is that the median time to transformation/MDS is over 4 years, so no meaningful change in median overall survival.

"Still," Daniel adds, "it should be noted that Dr. Treon states in his 'How I treat WM' article in the journal *Blood* that he does not prescribe purine nucleosides to patients younger than 70."

**Renee** then wrote to say that since there may now be a consensus among the WM experts to avoid the nucleoside analogs (e.g. 2CdA, fludarabine) altogether, she had learned something of importance from reading TALK and that the

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



fact remains, however, that doctors around the country are still recommending nucleoside analogues. These drugs are still being used in clinical trials, and many patients have benefited from them.

**Renee** had been treated with solo fludarabine 12 years ago with minimal side effects and (to date) no MDS or transformation. But, as **Tom Hoffmann** has pointed out, Renee may have permanent bone marrow suppression: “We are all guinea pigs in the treatment of this disease with no completely effective and non-toxic regimen available.”

So we see again and again how the dynamic nature of TALK interaction helps readers gather information to consider (remember always that TALKers are for the most part not licensed practitioners!) and fold into their decisions in concert with their doctors about how to treat.

Other topics of interest in the late-summer/autumn months on TALK included managing anemia, flu vaccines, solid tumors,

cryoglobulinemia, and plasmapheresis.

One final thought as we enter the New Year comes from **Nancy Ruiz-Stupi**, the wife of **Hank Stupi**. Asked by her husband how she felt when she accompanied him to the infusion room for his treatments, Nancy wrote the following reply which Hank shared with TALK readers: ‘There are (I’m certain) many different feelings that occur in such places, such as fear, frustration, impatience, feeling physically unwell, and likely some denial as to their particular situation. But overall, I would have to say, there is a great deal of hope in those places; hope that this treatment will do the trick and return them to a semblance of normalcy; hope that they can return to the home they feel most comfortable in; hope that they will be able to witness the birth or graduation or marriage or birthday of a loved one; and hope that they will be given more time to do the things they love and spend time with the people they love.’

Here’s our hope for 2010: the best of health to everyone!

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## COOKS’ HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

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*Penni and Nancy are traveling this issue – from Greece to Spain and back to their kitchens as they sample healthy foods and snacks, simple to prepare and full of Mediterranean ingredients.*

When in Greece, home from Greece, or just thinking of Greece, roast potatoes with lemon and oregano as our intrepid *Torch* editor, Alice Riginos, does. She learned the method from her Greek mother-in-law. And as strange as it might seem to some to be talking of fresh potatoes in the dead of winter, this, right now, today, is potato season. Freshly dug potatoes are full of moisture and have thin, almost shaggy skins. The season extends through early spring. These tender potatoes should be stored in the refrigerator.

You could well accuse us – Alice, Nancy, and me – of being carbocentric and you might be right. Visions of crispy, roasted potatoes float in our heads, perhaps roasted with chunks of sweet potatoes and/or winter squash as well. Nancy then tosses the roasted potatoes with apple and vinaigrette to make a wintry potato salad. Try adding some toasted, chopped walnuts as well.

While I would layer the roasted potatoes with caramelized onions and Petit Basque cheese and then run the whole thing under the broiler until the cheese bubbles. If there is cooked bacon or sausage in the house, that goes in the mix as well. You could serve this as a hearty snack, or even for supper with a salad.

For those of you who would prefer a lighter (New Year’s resolution, perhaps?) but no less savory potato topping, Nancy suggests Greek-style nonfat yogurt. It’s very thick and just mildly tangy. She uses it as a substitute for sour cream, and

makes a version of the Greek sauce/dip/condiment *tzatziki* – a blend of mashed garlic, diced cucumber, salt, pepper, a splash of lemon and olive oil and perhaps a bit of dill.

While we’ve drifted off the potato topic for a moment (we will return soon) but are still in Greece, we must, yes, must mention Greek honey. Clear, fragrant with the flowers and herbs growing on the mountainsides, and so thick it wraps around a spoon and doesn’t drip. With such a honey or another very good one, make a dessert like one Nancy had in Barcelona (yes, I know, suddenly we’ve leaped to Spain. But that is where she had it and you might have too, or had one like it in any country ringing the Mediterranean.) Anyway, just pour good honey over Greek-style yogurt, sprinkle on some toasted almonds and enjoy it for breakfast, a snack, or dessert.

And since I cannot get my mind off dessert, I’ll pass on a trick I just learned to take some of the calories out of whipped cream: whip heavy cream very stiff and then fold in an equal amount of Greek-style nonfat yogurt (if you used 1/2 cup cream, fold in 1/2 cup yogurt), a little sugar or sugar substitute, and some vanilla.

Herewith, without any further jumping about, our *raison d’être*: Oven-Roasted Potatoes from Alice by way of her mother-in-law.

“The wonderful thing about this dish is the flexibility. Almost any type of potato will respond, although I prefer red potatoes in the spring. Roasting time and temperature are also flexible. If you are in a tear to get food on the table, you can set the

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*Cooks’ Happy Hour, cont. on page 23*



oven at 375 degrees F or a bit higher and have perfectly acceptable potatoes in an hour.

“But really wonderful results come from slowly cooking the potatoes for about 2 hours at around 300 degrees F. This is very useful for parties as you can put them in the oven and then go about other preparations.

“Preheat the oven and peel the potatoes, if desired, and then cut them into evenly sized chunks. Choose a roasting pan that gives the potatoes room to spread out but not get lost. I use Pyrex but any type will do. Toss the potatoes with a generous dose of very good olive oil “Alice is a purist about sticking to olive oil, lemon juice, oregano and salt and pepper; but if you have any duck or goose fat leftover from the holiday bird, and feel more daring, add some of that, too”, the freshly squeezed juice of at least one lemon, maybe two, depending on how many potatoes there are. Season with salt, pepper, and a very good sprinkle of very good oregano. Stir everything all around.

“Turn the potatoes every so often; they will stick if left unattended. If they are drying out, add some water – not too much – maybe more lemon “or dry white wine”, but be judicious. The slow roasting method gets the potatoes crispy on the outside and sweet inside, but they shrink, too, especially if left too long and get overcooked. Timing can be controlled by increasing or decreasing the temperature and there is no adverse effect on the potato. If they are tasting fine but have poor color, fire up the broiler, and give them a minute to turn brown.

“As I mentioned, the oregano is key. Really good, freshly dried oregano infuses the house with an irresistible smell

and the potatoes with its taste. In the ‘old days’ when our daughters were young and their parents peppier, we would do a Greek Easter celebration with lamb on the spit in the backyard. There were lots of early morning preparations. I would get two large pans of potatoes going very, very slowly as soon as I could. If the oven was needed for something else, out came the potatoes; covered with foil, they could wait until the oven was free again. Many of the other Easter foods had dill as the main herb flavor. The oregano was a welcome contrast.

“Tiny new potatoes in their skins can also be roasted in this way. They are very appealing in an array of *mezedes*. Even at room temperature, they taste fine with a glass of ouzo.” Or you might try dipping them in Nancy’s low-fat spinach dip:

“I use a 10-ounce box of spinach, defrosted, and squeezed dry, which may be around a cup or so, if you are using fresh, cooked, chopped spinach. I mix this with around 1/2 cup fat-free cream cheese, 1/2 cup Greek-style yogurt, 1/2 cup low-fat shredded cheese such as cheddar or whatever I have on hand. If the consistency is too thick, I just add more yogurt to make a nice dipping consistency. For flavor, I add a little hot sauce, minced garlic, grated onion, a zippy mustard (such as brown or Dijon), and some fresh or dried herbs as a salt substitute. I serve it with roasted potatoes, baked bagel chips, and fresh veggies.”

**Our motto: Eat Well to Stay Well**

Fans of *Cooks' Happy Hour* will want to wander the culinary world with Penni at her new website: [www.penniwisner.com](http://www.penniwisner.com)

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## SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

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A very warm welcome to the newly formed WM support group in Ireland. An account of their inaugural meeting at the home of a Dublin member appears below. Also reporting for the first time is the French group, who record the details of their meeting on a beautiful autumn day in Vienne, France. Not that it’s a contest, but the Finnish support group provides a glowing account of their fourth annual meeting, a weekend retreat, this year on an island off the coast of the historic city of Turku.

*Please note: Contact information for all support groups is printed on pages 29-30.*

### INTERNATIONAL

#### FINLAND

The Finnish WM group had its annual seminar in Turku in September, 2009. Autumn weather was on its best behavior when patients and family members, 43 in all, made their way from various parts of Finland for two days in the historic southwestern city by the sea. The venue was Meri-Karina, a hotel/spa on an island connected by a bridge to central Turku. Operated by the Southwestern Finland Cancer Organization, the hotel presented a calm and welcoming environment for the weekend’s activities.

The program included an informative talk by Turku University Medical School lecturer in hematology, Dr. Marko Vesanen. His topic covered the latest WM treatment options,



*The Finnish WM group held its annual meeting at Meri-Karina, a hotel and spa operated by the Southwestern Finland Cancer Organization.*

*Support Group News, cont. on page 24*



and he also offered some visions of the future of WM treatments. Dr. Vesanen had time to answer questions from the audience and gave us an opportunity to better understand the choices that our attending physicians have made. Group discussions were also part of the weekend, giving newly diagnosed patients the opportunity to meet with those with years of experience of living with WM. The discussions were led by psychologist Riikka Koskinen and group leader Veikko Hoikkala.

Spouses and other people close to WM patients had their own support group discussion which was led by psychologist Leila Hoikkala. Saturday's program concluded with a fine dinner with entertainment. Later there was an opportunity to use the hotel's sauna and pool before participants settled into Meri-Karina's peace and quiet for the night.

Right after breakfast on Sunday, there was an opportunity to attend a short prayer service at Saint Henry's Ecumenical Art Chapel, a striking example of award-winning modern architecture situated right next door to Meri-Karina. The chapel and gallery were introduced by Meri-Karina's managing director Kari Ojala, and church musician Leena Suominen presented a well chosen music program. For many members of the WM group, music is a meaningful part of spiritual life. Sunday's session provided an opportunity to sing together and to experience the chapel's wonderful acoustics.



Next door to Meri-Karina: Saint Henry's Ecumenical Art Chapel

The theme for Sunday's presentations was the mind-body connection. Finnish Cancer Organization's psychologist Riikka Koskinen had a presentation on the mind-body connection and how we can become more aware of it. The subject provoked a lively discussion and inspired the participants. The two-day seminar was organized by active WM support persons **Veikko Hoikkala** and **Leena Simonen**, with additional resources provided by the Finnish Cancer Organization and psychologist Riikka Koskinen. Based on the feedback received so far, attending WM patients and family members are already looking forward to next year's program! Meri-Karina made a lasting impression.

## FRANCE

A very sunny September day in Vienne, France, greeted the Waldenström and CLL French TalkList patients arriving for their meeting at the Institution Robin St. Vincent de Paul.

Fifty patients, spouses, and caregivers attended. They looked forward to meeting in person others they had known until then only in a virtual way.

The speakers included Dr. Xavier Leleu, who was a researcher for several years at the Bing Center for Waldenström at the Dana-Farber Cancer Institute in Boston, MA, USA. He is now a hematologist at Hopital Huriez, CHRU of Lille, France. Dr. Leleu gave a very comprehensive survey of the latest research and clinical findings on Waldenström. Another speaker was Dr. Nicolini, a hematologist at CHU Edouard Herriot, Hospices Civils of Lyon, France. Dr. Nicolini gave an excellent presentation on CLL. Both doctors generously answered all questions put to them. Throughout the day, great fellowship and gourmet breaks created a supportive atmosphere. During the delicious dinner, lively and cheerful conversation flowed. The event was such a success that the groups intend to meet again in another beautiful area this coming year.

Support Group News, cont. on page 25



At Vienne the French WM and CLL groups spent a full day hearing about advancements in research and enjoying the glorious autumn weather between "gourmet breaks."



## IRELAND

The first support group meeting for Irish WMers was held in Dublin in October 2009. Five patients and one caregiver arrived from all corners of Ireland to meet in the home of one of the group. They were so glad to make personal contact with fellow WM sufferers as they had felt isolated until then. The morning was spent listening to each other's stories during which they realized how varied each patient's story was – from one who has only just been diagnosed and is wondering what is in front of her to another who has been living with WM since 1994 and has been through so many ups and downs. After lunch in the local pub, the group returned to the house to watch parts of the 2009 IWWMF patient education forum DVDs. These were most interesting, if rather too much to take in at one sitting! The next meeting is planned for the spring of 2010 by which time the group hopes to have linked up with more WM patients from around the country.



Dr. Treon surrounded by members of the Sacramento and Bay Area support groups.

## USA

### ARIZONA

On December 14, a meeting of the Phoenix area support group was held at the Mayo Hospital. There were approximately 20 attendees and the speaker was Dr. Joseph Mikhael. Several attendees had dinner together afterwards. Dr. Mikhael's presentation was very well received, and the group is planning another meeting in the near future with Dr. Fonseca of the Mayo Clinic to tour his very special lab. For details about the upcoming meeting, contact support group leader Ed Nadel 480-502-5045 or enadel63@aol.com.

### CALIFORNIA

#### Los Angeles

The Los Angeles support group met with Dr. Herbert Eradat of the UCLA David Geffen School of Medicine. His talk covered the basics of WM and, more importantly, clinical trials being conducted at the UCLA Medical Center. Several trials are being conducted at this time, with more to come in the future. UCLA is making a new effort in working with WM patients and clinical trials, including one for the "human" version of rituximab. The center has currently close to 150 WM patients. Dr. Eradat was extremely articulate in explaining the disease and answered the many questions posed throughout his talk. There was a very good turnout; in fact, the room was completely full with members of the Los Angeles group, some from the Orange County group, and medical professionals. The UCLA Lymphoma Program provided a delicious dinner that was enjoyed by all.

#### Orange County

More than 70 people participated in the October meeting. Our featured speaker, Dr. Steven Treon, Director of the Bing Center at Dana-Farber Cancer Institute, brought us up to date on what is happening in the world of WM research. He expressed continued optimism about possibilities for improving outcomes from treatments that are being developed and tested. Dr. Treon's extensive presentation covered historical, current, and upcoming efforts in research, development, testing of new treatments, both solo and combination form. He acknowledged the \$1 million grant IWWMF provided the Bing Center. Because his appearance came early in the flu season, a popular question concerned vaccinations. Dr. Treon spoke in favor of the killed version of the H1N1 vaccine but recommended against being inoculated for shingles because it is a live virus. Our meeting's success was enhanced by the efforts of several members to provide A-V equipment, our local LLS coordinator's efforts to keep us well stocked with refreshments and to provide collateral material, and our visiting Dr. Eradat's emergency provision of a backup computer!

#### Sacramento and Bay Area

In October Dr. Morie Gertz of the Mayo Clinic visited San Francisco as part of the Lymphoma Research Foundation's San Francisco weekend workshop. Dr. Gertz gave his garden lecture ("think of your bone marrow as a garden; the WM cells are the weeds"). What is so striking about Dr. Gertz's presentations is that he speaks in such simple, clear language and suddenly you discover you understand something about WM that is brand new to you. It is an amazing gift. Dr. Gertz spoke for about an hour, answered some questions, joined us for lunch, and then returned to answer more questions. Our good fortune extended into November when Dr. Treon returned to the Bay Area and gave us his updated presentation. The good doctor, accompanied by his two sons and his right-hand man, Christopher Patterson, dispensed that most essential and priceless medicine: hope. We were so excited by our sneak peak at data to be presented at the ASH conference in December that we passed the hat and raised \$1753 to further fund Dr. Treon's research.



### COLORADO & WYOMING

Dr. Martha Lacy from the Mayo Clinic, Rochester MN, met with the group in November. Martha grew up in Denver and came to visit our group as well as her family. Almost 60



Dr. Martha Lacy (Mayo Clinic) gave an excellent overview of WM for the Denver support group. Shown left to right: Bill Bass, Dr. Lacy, Dr. Jeffrey Matous (Denver oncologist, a frequent participant in the support group), and Roy Parker.

people, including 6 newly diagnosed patients, attended at Presbyterian St. Luke's hospital. This meeting was hosted jointly by the IWMF and the LLS. They provided a nice breakfast and helped arrange the large conference room. Dr. Lacy was introduced by our local expert WM doctor, Dr. Jeffrey Matous of the Rocky Mountain Cancer

Center. Dr. Lacy shared her perspective of the definition and diagnosis of WM, new treatment options, clinical trials, and future research plans. She took questions for almost an hour following the presentation and received great acclaim for her answers being so clear and easy to understand. Dr. Steven Treon will speak to the group February 20 in Denver.

### FLORIDA

*Ft. Lauderdale area*

Approximately 30 attendees participated in the September meeting, including members from as far away as Sarasota. Once again, the group was fortunate to have Dr. Daren Grosman, Director of the Leukemia and Lymphoma Program of Memorial Cancer Institute, there to answer questions concerning Waldenstrom's. Dr. Steven Treon will visit for a meeting early in 2010.

*Southwest Florida*

The southwest Florida group will meet on Saturday, March 13, 2010, from 1 to 4 pm at the Hampton Inn in Sarasota. Steven Treon, M.D. will be the speaker.

### GEORGIA

In October the group hosted a big meeting including contingents from both North and South Carolina to hear Dr. Steven Treon at Emory University's Winship Cancer Institute. Winship is the first medical facility in Georgia to earn this coveted National Cancer Institute's Cancer Center designation. As an NCI designated center, Winship joins an elite group of 64 cancer centers nationwide that are on the forefront of the battle against cancer. Dr. Leonard Heffner of Emory spoke at the meeting as well, updating us on currently available treatments. Dr. Heffner has between 15 and 20 WM patients, consults regularly with Dr. Treon, and attends many of the medical WM conferences. The next meeting will be in February when we intend to have an oncology dietitian speak to our group.



Dr. Robert Kyle spoke to the Chicago area support group without leaving Mayo Clinic. WebEx technology allowed Dr. Kyle to address the audience in Chicago and conduct a lively question and answer period afterwards. Note in the photo that the auditorium was full but the podium was unoccupied!

### ILLINOIS & SOUTHEAST WISCONSIN

The Chicago group had a great meeting in October at its usual location, the Luther General Hospital in Park Ridge. This meeting was special for two reasons. First, it included southeastern Wisconsin for the first time, and second, we had the first IWMF video conference from Mayo Clinic using WebEx. Dr. Robert Kyle, IWMF Board Member and world-renowned WM expert, was able to speak to a large audience in the Chicago area assembled in the Lutheran General Hospital auditorium. Dr. Kyle not only gave one of his famous presentations, he also spent more than one hour answering questions using the interactive video capability of WebEx. The attendees were very thankful to be able to address Dr. Kyle in this personal format. All expressed sincere appreciation for his helpful responses. The next regular meeting is planned for the spring; in the meanwhile, we plan small group pot-luck dinners in January and February.

*Support Group News, cont. on page 27*



**IWMF Joins the Red Sox**

IWMF member John Paasch was on hand at Fenway Park on World Lymphoma Awareness Day when the Red Sox's President / CEO, Larry Lucchino, and star pitcher, Jon Lester – both lymphoma survivors – received awards from the International Lymphoma Coalition. Jon, on the far right, was "honored to join the line-up".



### NEW ENGLAND

#### Boston

New England recently held a couple of meetings. At the first, Trish Sheehy, nurse practitioner for Dr. Steven Treon, discussed coping with a chronic illness like WM. Trish also took questions from those in attendance about various WM issues. At the second meeting, Dr. Treon himself made a great presentation of all the work that has been going on at DFCI and the Bing Center. Much of what Dr. Treon shared was brand new information that was recently cleared by the American Society of Hematology and presented in December 2009 at their annual conference. A special thanks to Dr. Treon and to Chris Patterson for hosting; they had taken the red-eye home to Boston from their appearance the day before at the northern California support group.

### NEW YORK

#### New York City

It is clear from the number of newly diagnosed attending meetings that people are finding the IWFM quickly and easily. Dr. Richard Furman of Weill-Cornell Medical Center spoke at the September meeting, drawing his usual large crowd. This was his third time speaking to the NYC group. He gave an update of current clinical trials and answered many questions in an informal format. In October, NYC support group members were well represented among the 50 or so WM patients attending the Lymphoma Research Foundation's North American Education Forum in Brooklyn. Other support groups represented included Philadelphia, Albany, and Connecticut. NYC group members had assisted with the organization of the LRF forum. See page 4 of this issue for coverage of the LRF forum in Brooklyn.

#### Eastern NY/Western New England

Lively discussion punctuated the November meeting at Gilda's Club in Latham, NY. 2010 program dates were chosen, members volunteered for needed tasks, the April IWFM forum in Las Vegas was promoted, and the recommendations for and availability of the flu and H1M1 shots were debated. After a delicious pause for lunch including not just one but several home-baked deserts, members swapped information about their latest doctor visits and test results. Then the group decided to watch the two Rituxan presentations and the first case study from this past May's WM Patient & Physician Summit held at Dana-Farber. The tentative 2010 schedule

is to hold meetings on January 30, May 22, September 25, and November 13. The annual restaurant outing to stifle the winter blues will be on March 13 or 20; and our annual summer picnic will be on August 21. The very informal, friendly (and healthy!) bunch welcomes any WMers in the area to the programs.

### NORTH CAROLINA

Initiated in February 2009, the still new North Carolina group met for its third meeting in November. Seven members met along with six caregivers. Dr. James Radford of the Hendersonville NC Hematology and Oncology Group made a presentation. The group agreed that, using a DVD that he prepared, Dr. Radford made the clearest explanations of WM they had ever heard. He also answered questions from the group specific to their concerns and experiences. One group member reviewed what she had learned about obtaining financial aid for patients in treatment from the LLS.

**Don Nolan** delivered a brief summary of Dr. Treon's presentation to the Atlanta support group. Three couples from the North Carolina group had attended the Atlanta meeting. The Margaret R. Pardee Memorial Hospital in Hendersonville provides meeting rooms and publicity for the North Carolina group. The group's next meeting will be scheduled for early 2010.



Chinese medicine was the focus of the recent support group meeting when David Mortell, a registered acupuncturist in private practice, demonstrated his skill.

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

East meets West: Support group members, family, and friends gathered in November at the home of **Marcia and Glenn Klepac** to gain insight into Chinese medicine, including acupuncture and its application to cancer treatment and prevention. David Mortell, a registered acupuncturist with a private practice in the Pittsburgh area, was the featured speaker. David shared his expertise in an informal, interactive manner which included an acupuncture demonstration with **Cynthia Peterson-Handley** (sister of Marcia Klepac) as willing volunteer (shown in photo). The speaker emphasized the essential role of nutrition in cancer care including recommended resources. The afternoon concluded with our traditional pot luck dinner, sharing of personal stories, and support. Group members not present who are facing health challenges at this time were remembered with good thoughts and cards.

### SUPPORT GROUP LEADERS TALK LIST

This list is only for support group leaders to use in communicating with each other about support group issues. It is designed for the leaders to share their experiences and ideas for facilitating our IWFM support groups. Contact Cindy Furst at [cindyfurst@msn.com](mailto:cindyfurst@msn.com) if you would like to participate.



### **WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY**

In October at the Upper Valley Medical Center, the center's nutritionist addressed the group on the topic of nutrition and cancer. The first part of the meeting was a test of sorts; attendees were asked to write down what they had eaten the previous day for breakfast, lunch, and dinner, plus any snacks. They then compared their intake with the food pyramid. Many questions were asked during the presentation. The importance of phytonutrients to a healthy life style was held up as a goal to strive for.

### **OREGON/SOUTHWEST WASHINGTON**

The group continues to enjoy the joint support of both the IWWMF and the LLS. Our quarterly meetings are usually in Lake Oswego on the fourth Saturday of January, April, July, and October; our tentative schedule for 2010 will be January 23, April 24, July 24, and October 23. This fall we rescheduled our October meeting to September in order to take advantage of a visit by Dr. Morie Gertz while he was in Portland. Dr. Gertz gave a one-hour presentation to a joint multiple myeloma and WM group about both myeloma and WM. The WM support group met immediately following his presentation. For people who live in Oregon and SW Washington, you can receive IWWMF e-mail reminders 3 to 4 weeks prior to each scheduled meeting. If you do not receive these e-mails and would like to, contact the IWWMF office in Sarasota, FL and ask to be added to the IWWMF e-mail list and to the Oregon/SW Washington mailing list.

### **PENNSYLVANIA**

#### *Philadelphia*

Sixteen members of the Philadelphia support group and their mascot, Heidi, held a meeting in October at Bryn Mawr Hospital. They discussed program ideas for future meetings. All agreed that sharing was the most beneficial type of program and that an occasional speaker or a video presentation were valuable as well. Also discussed were H1N1, peripheral neuropathy, amyloidosis, low platelets, osteoporosis, and other problems of aging which are not necessarily related to Waldenstrom's. After the meeting, delicious refreshments brought by one of the members fueled more casual conversation. In December the group met again to view the "Ask the Doctors" DVD from the 2009 Ed Forum, followed by discussion.

### **SOUTH CAROLINA**

In October, the South Carolina group joined forces with the Georgia group for a very informative presentation by Dr. Steven Treon on existing and promising new treatments for WM. In December, the group met at **Roger and Barb Robinette's** community clubhouse along beautiful Lake Greenwood, where they socialized and compared symptoms and treatments. The next meeting will be held during late spring.

### **TEXAS**

#### *Dallas & Northern Texas*

The group participated in a November video conference with Robert A. Kyle, M.D., from the Mayo Clinic in Rochester MN. Dr. Kyle gave a comprehensive overview of WM and its treatment and answered group members' questions. His Power Point slides could be easily seen, and Dr. Kyle and the group could see and hear each other in real time. The video conferencing system, called WebEx, was provided by the IWWMF and was coordinated by IWWMF Board member **Don Brown** in Chicago. The video conference was recorded and may be made available to other support groups. The next meeting will be on January 16 at Baylor University Medical Center in Dallas.

#### *Houston*

In order to broaden our scope, the Houston IWWMF group has teamed up with the Houston Cancer Institute and the LLS. Meetings are on the last Monday of the month at 1 pm at HCI, 1220 Blalock, Suite 200, Houston 77055. The space is conveniently located 2 minutes off of I-10, Katy Freeway, and 5 minutes from 610 Loop, and 3 minutes from 290. There is plenty of free parking at the door. Refreshments are served, and we always have a speaker, regularly an oncologist, psychologist, or other support professional. All topics support WM patients and their caregivers. Family and friends are also encouraged to attend. There is no charge for these sessions, thanks to the support of HCI and LLS. In January, Dr. Maria Scouros will speak on "Why One WM Treatment and Not the Other." Dr. Scouros is the Director of the Houston Cancer Institute. Please check the HCI website at [www.HoustonCancerInstitute.com](http://www.HoustonCancerInstitute.com) for a list of program speakers and other events supportive of the cancer journey.

### **WASHINGTON D.C./METROPOLITAN AREA**

At the informal November meeting members brought each other up to date on their current WM status and treatments, an always helpful discussion for newly diagnosed WMers. Speakers for 2010 include Dr. Badros of the University of Maryland and Dr. Mary McMaster of the National Institute of Health in March.



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If you can't get to a local support group meeting, use our IWMF Telephone and E-mail Lifeline to call a WM veteran. The Lifeline provides telephone numbers and e-mail addresses of IWMF volunteers who will answer questions about their first-hand experience with specific treatments for WM.

*\*The Lifeline is seeking volunteers who speak a language other than English. If you would like to volunteer, please contact the IWMF business office at 941-927-4963 or info@iwmf.com.*

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**In memory of Helen Batdorf:**  
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**In honor of Maria Anna Colosi:**

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**In honor of Cristos Emmanouilides, M.D.:**

Lynn Bickle

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Ian Miller

**In honor of Jeremy Hinchcliffe:**

Hubert & Jean Hicks  
Perry & Karen McLean

**In honor of the 2009 NFL Season:**

Tom Ferraro

**In honor of Mike Pennington:**

Karen Blocksom

**In honor of Karen Pindzola:**

Kathy Pindzola

**In honor of Jon Randall:**

Franklin Chiles  
Heidi Chiles  
Julie Miller  
David Randall  
Harry & Jan Soza  
Paul Troy of Troy Risk, Inc.  
Donald & Sherrie Weis

**In honor of Laurie Rude & Peter Betts:**

Jim & Barb Bunton

**In honor of Norman Thompson, M.D.:**

Michael Adickman  
Martin & Patsy Heiland  
John Spellman

**In honor of Tom Thompson:**

WM Holly Hodge Farm

**In honor of Dr. Steven Treon's Research:**

IWMF Northern California Area  
Support Group

**In honor of Marcia Wierda:**

Judy Motman  
Betty Terhaar

**In honor of The Wickert Family:**

Denis Duchesne

**In honor of Bob Zehner:**

Alyson Zehner

*The View on Velcade, cont. from page 7*

occur, it was generally milder. The overall response rate in this study was 83%.

Newer proteasome inhibitors are being developed as well, and it is hoped that fewer side effects will result from their use. One of these is carfilzomib (PR-171), which is in Phase II trials for relapsed multiple myeloma patients. A Phase I dose escalation study of this drug included relapsed WM patients and reported a maximum tolerated dose of 15 mg/m<sup>2</sup> administered for 5 consecutive days within 14-day cycles. So far, carfilzomib appears to cause a much lower incidence and degree of peripheral neuropathy in multiple myeloma patients. It has been given "orphan drug" designation by the U.S. Food & Drug Administration for the treatment of multiple myeloma and WM. The Orphan Drug Act (ODA)

provides for granting special status to products to treat rare diseases or conditions upon request of a sponsor and provides tax and marketing incentives for these products. Proteolix, the maker of carfilzomib, is also actively working on an oral proteasome inhibitor called PR-047 and hopes to begin testing it shortly in Phase I studies. Nereus Pharmaceuticals has developed a proteasome inhibitor called NPI-0052. Preclinical studies suggested that NPI-0052 may be superior to Velcade in rapidity of effectiveness and duration of response and is even active in multiple myeloma cells that are resistant to Velcade. Currently in several Phase I trials for lymphoma, leukemia, solid tumor, and multiple myeloma patients, NPI-0052 is being administered as once-weekly, dose escalating IV infusions.





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