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Bing Center for Waldenström's Macroglobulinemia Newsletter

September 2010

Dear Patients & Friends-

With Autumn setting on the horizon, this issue of our newsletter contains a variety of information on Clinical Trials, corresponding with your specialist, and a very special section on the **Walter Reed Medical Center** in Washington DC, Autumn Health Tips for the season, and upcoming Support Group meetings with Dr Treon guest lecturing.

Clinical Trials- Take II

Now that a majority of people have enjoyed their Summer plans with family, vacations, and gave their brains a hiatus from everything, I wanted to keep this section of the newsletter from June 2010 just incase someone decided to shelve this information until now. Please keep in mind that if and when you are participating on a Clinical trial and have any kind of question during your time on a clinical trial, please contact your clinical trials coordinator and if you are suppose to keep a journal of your responses, please be accurate and detailed. Journals are for your benefit in order for the care group to help you to the best of the Clinical trials ability. Journals are not last minute homework prior to seeing the NP or physician, but vital information for the proper direction you need to be taken within trials.

Just to generalize, although there are many definitions of clinical trials, they are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol. ClinicalTrials.gov includes both interventional and observational types of studies. Interventional studies are those in which the research subjects are assigned by the investigator to a treatment or other intervention, and their outcomes are measured. Observational studies are those in which individuals are observed and their outcomes are measured by the investigators.

To inquire about the current clinical Trials that exist at the Bing Center for Waldenström's Macroglobulinemia, you can find the current roster at the National Cancer Institute website:

<http://www.cancer.gov/search/ResultsClinicalTrials.aspx?protocolsearchid=7856626>

After reviewing the various clinical trials and you have some questions, please contact us for further explanation and clarification. One of our clinical research coordinators will be happy to assist you.

Many of the listed clinical trials are within the WMCTG (Waldenstrom's Clinical Trials Group) consortium found on www.wmctg.org and work in relation with the Bing Center for WM. For other prospective clinical trials in your area, you can find them on the NCI's website search area, <http://www.cancer.gov/clinicaltrials/search> and fill in the required location information.

Tips for emailing your health-care provider

After your regular visit, or new consultation here are a few tips to help you understand what you should do once you return safely home from your visit.

1. Clinicians **CANNOT** safely diagnose or treat a patient via email. Email is used for general questions only. Email should never be used for urgent/emergent issues. Please do not rely on time-sensitive issues. For a routing issue during your visit, please allow up to 5-7 business days for a response due to many departments processing your visit (i.e. CT scans, MRI's, Blood count readings, or even special exams such as neuropathy or eye exams).
2. When sending an email, always include your full name AND either date of birth or medical record number in the body of your email. Believe it or not, there are a lot of people in the world with the same names and even the same cities or states. By stating this information, it will help the care group find your history and records and be able to communicate with you when calling you by phone.
3. Please make emails short and clear. Do not assume email is confidential. Email can occasionally go to the wrong party because of a keystroke error.
4. If you happen to visit your local physician or other specialists, please make sure that they have sent your oncologist copies of their physician's notes of that particular visit. Once they are received, they are added to your file and examined by the care group prior to your next exam. By having this information, everyone is current with your health care.
5. If you are a patient of the Partners Organization (Dana Farber, Brigham & Women's, Mass General Hosp.), the fastest way to receive lab results and check appointments is by registering for www.patientgateway.org. If you are not of a Partners Organization, then check with your oncologist for their own Institute, Hospital, or Center's gateway system.

Things to keep in mind about the Internet:

Not all websites are created equal. Information can be outdated or incorrect. Medical information on the Internet or emailed to you by a healthcare provider does not necessarily apply to all patients. The National Institute of Health has instructions for evaluating websites: <http://www.nccam.nih.gov/health/webresources/D337.pdf>

WM dedicated Websites:

www.wmctg.org



This website is devoted to the Waldenström's Macroglobulinemia Clinical Trials Group. It is a resource for patients interested in the status of WM-related clinical trials, as well as links to general information about WM to a physician located close to home.

- **Physicians (USA):** List of the 15 USA-based physician members of the WMCTG and their locations.
- **Physicians (Int'l):** List of the 8 international-based physician members of the WMCTG and their locations.
- **Physician Pages:** Photos and biographies of each physician, as well as links to their corresponding institution websites (where available) and contact info. Each physician also has a link to the NIH website (ClinicalTrials.gov) showing their WM-related clinical trials (where applicable).
- **Contact Us:** An online form where comments or questions may be submitted for review by a WMCTG member.
- **Additional Resources:** Links to related websites.

www.BingCenterforWM.org



Constant updates are being made to our main Bing Center website in order to keep the content up to date.

- **WM Diagnosis & Therapy:** Treatment recommendations for WM, and abstracts.
- **About Our Program:** Description of the Bing Center, clinic and staff.
- **News & Events:** Announcements for recent and upcoming conferences and support group meetings. All posters from the recent ASH 2009 conference have been posted here.
- **Clinical Trials:** Updates to current and pending clinical trials, and participating institutions.
- **Basic Research:** Updated with our most recent research projects and studies.
- **Publications:** Updated with our most recent abstracts and published papers (i.e. "How I Treat Waldenström's Macroglobulinemia" by Dr. Steven Treon).

Steven P. Treon MD, MA, PhD

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Dedicated to the Discovery of the Cause and Cure of Waldenström's Macroglobulinemia

Dr. Steven Treon is the Director of the Bing Center for Waldenström's Research and an attending physician for medical oncology, at Dana-Farber Cancer Institute and Brigham and Women's Hospital, in Boston, Massachusetts. He is also an Associate Professor of Medicine at Harvard Medical School in Boston, and is the Chair of the Waldenström's Macroglobulinemia Clinical Trials Group.

After earning a doctorate in tumor immunology from Boston University (BU), Dr. Treon did a postgraduate fellowship in the Department of Microbiology at BU School of Medicine. Dr. Treon received a medical degree from BU School of Medicine and completed an internship in medicine and a residency in internal medicine at BU Medical Center. Dr. Treon also served a clinical fellowship in hematology and oncology at Mass General Hospital and a research fellowship at Dana-Farber Cancer Institute and Harvard Medical School. He received certification from the American Board of Internal Medicine in 1995, and in medical oncology in 1997.

Dr. Treon's main research interests focus on understanding the genetic basis and pathogenesis of Waldenström's macroglobulinemia and the development of therapeutics for this malignancy. He serves on the editorial boards of the Journal of Clinical Oncology, Blood, Clinical Cancer Research, and The Lancet. Dr. Treon is a member of several professional societies including the American Medical Association, American Society of Hematology, American Society of Clinical Oncology, European Society of Hematology and the Massachusetts Medical Society. He has been honored with several research and academic awards from various national and international medical foundations and institutes, including the Robert A. Kyle Award for Waldenström's Macroglobulinemia.

[Click this link to download a pdf version of Dr. Treon's CV.](#)

Featured News Items and Photos

Over 600 patients and caregivers joined an international faculty of experts during the 3rd International Patient and Physician Summit which took place May 1-3, 2009, in Harvard Hall, at the Harvard Club in Boston, MA. Dr. Steven Treon of the Dana-Farber Cancer Institute chaired the 3 day event, during which time studies addressing the genetic basis, familial predisposition, pathogenesis, and treatment of Waldenström's macroglobulinemia were presented by 40 faculty members who represented universities and academic centers throughout North America and Europe.

Details of the program including abstracts and slide presentations are now available at www.wmsummit.org. The 4th International Summit on WM will be held March 10-13, 2011 at the Disney Village, Orlando, FL. Details and registration for this event will also be available at www.wmsummit.org.

The following websites contain valuable information regarding the research and treatment of Waldenström's Macroglobulinemia:

Please visit our main program website: Bing.Center.for.Waldenströms.Research. This site contains information on the latest treatment recommendations, abstracts, news and events, current and pending clinical trials and participating institutions, basic research, and publications, as well as photos and brief bios of the Bing Center staff.

Also feel free to visit our WWW.Workshop.Website. Please refer to our most recent conference which was held October 15, 2008 in Stockholm, Sweden.

Karen Lee Sobol addresses the attendees of the Prudential Skywalk Reception at the 3rd International Patient & Physician Summit, May 1-3, 2009 (click the photo to download a copy of the address). Please visit www.wmsummit.org for more photos from the Summit.



The official website of Dr. Steven Treon, its main focus is on Dr. Treon's research of WM. Constant updates have been made to the Publications and Media sections. The Home page has also been updated with information about the 3rd International Patient-Physician Summit, which was held May 1-3 in Boston.

- **Media:** Galleries of photos in several categories (Bing Center, Conferences, Support Groups). A new "ASH 2009" gallery has been posted here.
- **Papers & Publications:** Papers which Dr. Treon has authored or co-authored, sorted by year of publication. Also includes "featured impact articles".
- **Mailing List:** Patients can sign up to be on Dr. Treon's mailing list, to receive periodic updates (this newsletter, for example), or to change their contact information.
- **Comments:** A public message board, where patients can post messages & comments. Dr. Treon can also reply to specific comments where appropriate.
- **Contact Me:** Patients can send a confidential message to Dr. Treon by filling out & submitting the form on this page.
- **WM Info:** The complete description of Waldenström's Macroglobulinemia. Dr. Treon co-authored this paper with Dr. Giampaolo Merlini. A biography of Dr. Jan Gosta Waldenström is also included.
- **Patient Resources:** Links to our partner groups and organizations.

Welcome to the official website for the
**International Workshops on
Waldenström's Macroglobulinemia**

The International Waldenström's Workshop
Organizing Committee Proudly Presents

**The Sixth International Workshop on
Waldenström's Macroglobulinemia**

Venice, Italy
October 6-10, 2010



Learn about our upcoming and previous conferences

Workshop News

Stockholm 2008

Kos 2007

Paris 2004

Athens 2002

Washington 2000

Media / Abstracts

Home

Links

06.11.09 Venice 2010 Conference Dates & Venue Have Been Selected

We are pleased to announce that the Sixth International Workshop on Waldenström's Macroglobulinemia will be held on October 6-10, 2010, at the *Illegion Maline Study in Venice, Italy*. This is one of the premier properties in Venice. Please return to this website, as we will be providing more information, including the conference agenda, as it becomes available.



10.31.08 Stockholm 2008 Conference Section Has Been Updated

Abstracts and photos from the Fifth International Workshop on Waldenström's Macroglobulinemia in Stockholm, Sweden are now available online. Visit the [Stockholm 2008 section](#) of our site to

This website includes the upcoming information for the Sixth International Workshop for WM in Venice, Italy. The Physician conference is being held on October 6-10, 2010 with the IWMF patient-physician forum being held on the final day of the conference. For additional information on the IWMF forum in Venice, Italy, please go to www.iwmf.com

To research archival information from our previous five workshops (Stockholm 2008, Kos 2007, Paris 2004, Athens 2002, and Washington DC 2000), please visit the website.

The Summit's website's main focus is the Patient and Physician Summits on WM, which will be held every two years.

The upcoming **2011 Patient and Physician Summit will be held in Orlando, FL from March 11-13th, 2011**. Registration and details of the event will be posted within the next month.

Currently the content is based on the recent Third International Summit, held on May 1-3, 2009, at the Harvard Club in Boston MA.

www.wmsummit.org

International Patient and Physician Summits on WM

Harvard Club, Boston, MA, May 1-3, 2009

Home | Contact Us | Help

Welcome to the Third International Patient & Physician Summit on Waldenström's Macroglobulinemia

Official Website for the International Patient & Physician Summits on Waldenström's Macroglobulinemia

Over 600 patients and caregivers joined an international faculty of experts during the 3rd International Patient and Physician Summit which took place in Harvard Hall, at the Harvard Club in Boston, MA. Dr. Steve Treon of the Dana Farber Cancer Institute chaired the three day event, during which time studies addressing the genetic basis, familial predisposition, pathogenesis, and treatment of Waldenström's macroglobulinemia were presented by 40 faculty members who represented universities and academic centers throughout North America and Europe.

Highlighting the three day Summit were presentations offered by Drs. Anders Waldenström and Giampaolo Merlini who recounted the life and contributions of Dr. Jan Gosta Waldenström to the discovery of Waldenström's macroglobulinemia. On the final day of the Summit, six representative cases of WM were presented to the international faculty, who were called on to discuss their approaches to the care of these patients, highlighting the diversity of options now available for the care of patients with WM.

[Click here to download the conference program in PDF format](#)

SAVE THIS DATE!

The 4th International Summit on WM will be held March 10-13, 2011 at the Disney Village, Orlando, FL. Details and registration for this event will be posted to this website as soon as they become available.

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Disclaimers

- **Faculty:** Photos and biographies of the 27 faculty members who presented at this conference.
- **Abstracts:** Abstracts submitted by the faculty members, on topics to be presented at the conference.
- **Slide Presentations:** The presentations submitted by faculty members, and presented at the conference, organized into photo galleries for easy online viewing.
- **Media Gallery:** Over 200 photos taken at the conference sessions, as well as the Museum of Fine Arts, Prudential Skywalk, and 10th Anniversary Gala events.
- **Sponsors:** A list of sponsors and partners whose unrestricted grants made this conference possible.
- **Order DVDs:** An online order form for the complete set of conference DVDs, which include all sessions, panel discussions, and talks given at the events.
- **Contact Us:** An online form where comments or questions may be submitted to the conference organizers.

www.iwmf.com



The IWMF, International Waldenström's macroglobulinemia Foundation, is a dedicated non-profit, all-volunteer organization, developed and financed solely by patients and their friends and families. Its mission is to provide information, resources, a communication network, and experience on how to live with WM, plus encouragement to those affected by this rare and incurable blood cancer. For additional information, please contact Sara below.

Sara McKinnie, IWMF Business Office, 3932D Swift Road, Sarasota, FL 34231 Tel: (941) 927-4963 • FAX: (941) 927-4467 Email: info@iwmf.com

Waldenstrom's Macroglobulinemia lecture Walter Reed Medical Center



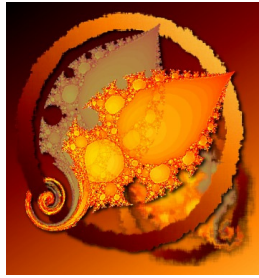
The Walter Reed Army Medical Center (WRAMC) is the hub of the Walter Reed Health Care System which provides comprehensive health care for more than 150,000 soldiers, other service members, family members and retirees. Walter Reed Army Medical Center, one of the largest medical treatment facilities within the entire Department of Defense. WRAMC has a long-standing reputation as one of the finest teaching institutions in the country. Medical officers nationally recognized for their skill, training and experience head WRAMC's department and services, and our educational professionals provide the ultimate in medical professional education.

Dr Steven Treon visited Walter Reed Army Medical Center (WRAMC) on Wednesday August 4th, 2010 under the invitation of MAJ Mark Roschewski and the WRAMC Hematologic Malignancies Department. The purpose of the visit was both educational for the trainees and staff at WRAMC as well as an opportunity for Dr Treon to visit with Soldiers who have been wounded in combat and those afflicted with hematologic malignancies. Upon arrival at WRAMC, Dr Treon visited with an 82nd Airborne Infantryman who was wounded in combat and is recovering from multiple orthopaedic injuries. The Soldier and his mother were both originally from the Boston area and appreciated the visit from Dr Treon given the mutual common interests. Another patient receiving inpatient chemotherapy for T-cell non-Hodgkin's lymphoma also received a visit from Dr Treon and the two discussed the process of his diagnosis while fighting in Afghanistan as well as the current status of his condition. The patient had been in charge of the medical evacuation process while deployed to Afghanistan and relayed his ability to see the importance of his job now that he was on the other end. Dr Treon provided expertise and insight into some possible options in the patient's care.

Next, Dr Treon met with the Hematology-Oncology fellow trainees at WRAMC in a small group setting to discuss recent cases of Waldenstrom's Macroglobulinemia (WM) currently being treated at WRAMC and provided tremendous guidance regarding the specific issues regarding each patient. Multiple cases were discussed and the trainees were offered an opportunity to discuss the complexities regarding the management of these patients. Last, Dr Treon gave a formal didactic lecture to both the staff and trainees at WRAMC as well as the National Naval Medical Center (NNMC) in Bethesda, MD via video-conference. Approximately 50 persons were in attendance to hear a state-of-the-art discussion surrounding the current biology and treatment options in the management of Waldenstrom's macroglobulinemia. Recent seminal discoveries presented at the American Society of Clinical Oncology meeting were discussed and time was allotted at the end for specific questions from the participants.

The trip was a resounding success offering both WRAMC and NNMC clinicians the opportunity to interact with a world-renowned expert in hematologic diseases as well as an opportunity for Dr Treon to get a "behind-the-scenes" look at the patients and providers unique to our military system of medicine.

Autumn Health Tips



I've done some sleuthing and have come up with some important tips to keep you swimming through the Autumn season, various holidays and battle-ready for the Flu season. It is very important to keep your entire body, mind, and habits fit and active!

Autumn, allergies, and bears..oh my! Well, I tried to be cute with the title, but the only advice I can give for bears is for purchasing non-Allogeneic Teddy bears http://www.ehow.com/how_10418_buy-teddy-bear.html in this Newsletter. Sorry.

Temperatures are dropping; trees are starting to shed their leaves. The garden and pavements need raking, but if you have seasonal allergies, better ask someone else to do it, or wear a mask while cleaning up. Raking them up will just stir up the pollen and mold spores, and will most likely trigger allergic reactions.

Most people are prepared for springtime allergies. However, they may neglect the allergies autumn brings with it. Autumn can aggravate two major allergies such as dust mite allergy and mold allergy. Dust mites are microscopic creatures which survive eating flakes of dead skin. They live in mattresses, carpets, furniture, bedding and places where they can feed on dead skin. Dust mites multiply in warm and humid environments. Dust mites themselves are not a problem, but their feces, shells, and their corpses produce allergy causing proteins. Washing the bed sheets and pillow cases regularly in hot water can decrease the dust mites. Mold is a type of fungus which breaks down the dead plant, animal matter and returns the nutrients to the earth. Molds grow in moisture and spread through spores. Spores are lightweight, tiny and can travel through air. People who have mold allergy are affected when they are exposed to mold spores. Keeping the house free from moisture is an effective way to prevent mold allergies.

Tips to Cope with Autumn Allergies:

Here are some tips to cope with autumn allergies:

Vacuum regularly: Vacuum your house using a HEPA filter enabled vacuum cleaner. While vacuuming, it is better to use a mask to prevent the dust from affecting you. Vacuuming regularly will keep the house clean and reduce molds and dust mites

Remove clutter: Having lots of stuff lying around makes cleaning harder and promotes the growth of molds and dust mites. Take steps to reduce the clutter by organizing books, paperwork etc. to keep the house dust free.

Use a dehumidifier: Molds and dust mites tend to grow in a humid environment. Use a dehumidifier and keep the humidity level in the house below 55%. By removing excess moisture and humidity, you will be able to control the allergies caused due to molds and dust mites.

Change air filters: Dust mites and spores of molds can become airborne and cause allergies. Changing the air filters once a month during autumn makes the filters more effective. The air will be clean and you can keep your house free from dust mites and molds

Over-the-counter medicines such as anti-inflammatory nose sprays or antihistamines are effective in dealing with allergies during autumn. If the symptoms persist, consulting your doctor is the best way. However, taking proper steps to prevent allergies before the autumn is the best way to deal with autumn allergies.

Keep your windows closed as much as possible, too, especially when hard winds are blowing. You may also want to check the pollen levels in your area (<http://www.aaaai.org/nab/index.cfm?p=pollen>) before venturing outdoors. Remember, if you suffer from seasonal allergies, you don't have to remain miserable. Seek your allergist for advice on which treatment is best for you.

Cold or Allergy?

How do you tell the difference between a cold and an allergy, and does it really matter? Yes, it matters. A wrong diagnosis can mean the wrong medication and treatment. And, though symptoms are similar (runny nose, coughing, sneezing, itchy throat, headache and watery eyes), there are ways to tell the difference:

1. Allergy symptoms can linger from August until the first frost. Cold symptoms generally last only a week or two.
2. A runny nose from a cold may turn yellow and green within a few days. Inside the nose, the mucosa is usually red and inflamed. With allergies, a runny nose remains clear and the mucosa is often pale and swollen.
3. Changes in the weather can affect allergy symptoms, but normally not a cold. A heavy rain will reduce pollen counts, resulting in improved symptoms. Dry, windy weather will raise pollen counts, resulting in worse symptoms.
4. Colds spread from person to person, through contact. Allergies don't. If one person in the household is sick for several weeks and no one else catches it, an allergy is the more likely cause.

**Upcoming Support Group meetings and latest information coming
from the Bing Center for WM.**

New England Support Group Meeting will be held **September 19, 2010** at the Dana Farber Cancer Institute. A special lecture will be given by NP Patricia Sheehy from the Bing Center on "*Natural History and treatment outcome of WM related peripheral neuropathy*". Please contact Lynn or Joe Mara at jmara@nordicgroupusa.com or Chris Patterson at cpatterson1@partners.org

Multi-State (NY-CT-NJ-PA) Support Group Meeting will be held on **December 14, 2010** and Drs Steven Treon from DFCI and Owen O'Connor from NYU will be lecturing on the Updates of WM: Genetics to Therapeutics. The lecture will be held at the Farkas Auditorium of NYU School of Medicine located 550 First Avenue at 33rd Street, New York, New York 10016. For further information about times and other details, please contact Chris Patterson at cpatterson1@partners.org, Neil Massoth (NY) at nmassoth@aol.com, Françoise Lampe (CT) at wmfgl@sbcglobal.net, and Karen Pindzola (PA) at karenpindzola@yahoo.com

The 4th International Patient-Physician Summit on WM will be held on **March 11-13, 2011** in Orlando, FL. This event will be a three-day event which will have 20+ international physicians speaking on many aspects of WM; Clinicopathological Basis and Pathogenesis, Treatment Options, Novel Treatment Approaches, Transplant Options, and Case Presentations for Waldenström's macroglobulinemia. More information, please go to www.wmsummit.org .

The 2nd Canadian Patient-Physician Conference on WM will take place in 2011. Further details will follow within the next Newsletter. If you wish to purchase a copy of the lectures given on DVD(s) from the Patient-Physician Conference held in Toronto, ONT, last October 2009, please contact Chris Patterson at cpatterson1@partners.org

Have a Safe and Healthy Autumn!

This newsletter is being sent as a courtesy to patients of the Bing Center for Waldenström's Macroglobulinemia. To be removed from this mailing list, or to change your contact information, please visit <http://www.wmprogram.org/Contact.asp> provide your name and email address, and specify your request in the message box.