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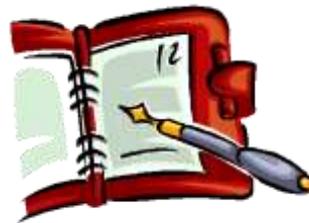
Bing Center for Waldenström's Macroglobulinemia Newsletter

September 2011

Dear Patients & Friends-

Now that Summer time is coming to a close and the brisk autumn has taken a direction of focus and guidance, some changes have been made at the Bing Center for WM. A new look and design on our website provides easier understanding, access, and mobility. Past lectures of Dr Treon have been added to YouTube for those who cannot attend meetings, and our research has taken a dramatic concentration on the *genomics and *familial elements of WM (*to be added in the November newsletter). Plans for the next WM Physician's Workshop are currently in production for August 2012.

Below are Highlighted events listed for the next couple of months as to the participation of Dr Treon and/or employees of the Bing Center for WM. For further information regarding any of these events, please contact Chris Patterson at cpatterson1@partners.org or any of the referenced contacts listed after the announcements.



September

17th- Little Compton, Rhode Island For those who are in the area and/or are interested in participating physically, monetarily, or spiritually, a few great Wmer's have spear-headed a "Walkin for Waldenström's" event this coming **September 17, 2011** in **Little Compton, Rhode Island**. Many of our Bing Center for WM staff will be participating in hopes of making this a strong, annual event!~ Proceeds benefit the Bing Center for Waldenström's. For more information, please go to the link <http://walkforwaldenstroms.org/home.html>

30th- Brooklyn, New York A special session on Waldenstrom's macroglobulinemia has been organized in conjunction with the Lymphoma Research Foundation (LRF) 2011 North American Educational Forum on Lymphoma. This meeting will be held on Saturday October 1, 2011 at the New York Marriott at the Brooklyn Bridge, and registration begins at 7:00 AM. At 11:00 AM, Dr. Steven Treon of the Dana Farber Cancer Institute at Harvard Medical School will present on Waldenstrom's Macroglobulinemia. Afterwards, Dr. Treon will answer questions from the audience.

Beginning on September 30th, we encourage you to take advantage of this two-day educational program which includes "Living with Lymphoma" breakout sessions and specialty topics and presentations on Current and Emerging Treatment Options. For further program information and to book your hotel reservations, visit www.lymphoma.org/edforum. or call 1-800-500-9976. The cost to attend is \$50 per person. Friday night reception, breakfast, lunch and dinner on Saturday and breakfast and lunch on Sunday are included. If you will be staying at the New York Marriott Brooklyn Bridge, your registration fee will be credited towards your hotel room charges. For more information, please contact Sara McKinnie at 941.924.4963 or the hotel web link at www.brooklynmarriott.com

October

9th, Williamsburg, Virginia An updated webcast lecture from Dr Treon for the VA Support Group Meeting will be held at 3:00pm at the VA Support Group meeting location. Please contact Bob Zehner, Support Group leader, bobnbetsz@comcast.net or 804.796.3571 for additional information.

16th, Toronto, Canada Attention all Canadians (or those who like to visit and walk around Canada!) For those who are or will be in the Toronto, Ontario, Canada area and are interested in participating physically, monetarily, or spiritually, a few great Canadian Wm'ers have spear-headed a Princess Margaret Hospital Walking or Running event this coming October 16, 2011 in Toronto, Ontario- Canada. You can support any area, clinic, or lab at the Princess Margaret Hospital which dedicates itself to the PMH Waldenström Macroglobulinemia Fund (WM Fund). Support/pledges for a rare cancer such as WM will support much needed medical research and patient support and education for our Canadian constituents. For more information, please go to the link www.pmf.ca/runwalk

22nd, Portland, Oregon Sponsored by the Leukemia & Lymphoma Society, there will be a WM lecture by Dr Treon held at the Fairfield Inn & Suites, 6100 SW Meadows Rd in Lake Oswego (just off the I5 freeway) from 12-2pm in the Garden Room. The education portion of the program would start at 12:30. For further details, please contact Patient Services Manager, Sue Sumpter at 800-466-6572 ext 2185 or www.lls.org/oswim

Welcome to the 21st Century for Information!



In order for many of our WMer's to see Dr Treon lecture, we decided to have two videos posted to YouTube. Both lectures are both from the IWWMF forum held this past June from Minneapolis, MN. Each video had to be split into segments less than 15 minutes (to conform to YouTube rules for new accounts). These videos are also posted to the Bing Center website's Media Gallery (www.bingcenterforwm.org) in their entirety:

Advances in the Treatment & Genetics of WM:

http://www.youtube.com/watch?v=pAzEIjwYz_o (part 1)

<http://www.youtube.com/watch?v=QNLn9DHDbI> (part 2)

<http://www.youtube.com/watch?v=YJz6Ef7fplg> (part 3)

<http://www.youtube.com/watch?v=jS4XWJ9jyv4> (part 4)

<http://www.bingcenterforwm.org/media-gallery/341-advances-in-genetics-and-treatment-of-waldenstroms-macroglobulinemia>

Ask The Doctors (panel discussion):

<http://www.youtube.com/watch?v=nYIa7bzkAQ> (part 1)

<http://www.youtube.com/watch?v=BGMCZKqQ11g> (part 2)

<http://www.youtube.com/watch?v=42DNq2k0Xpk> (part 3)

<http://www.youtube.com/watch?v=QW1M93RAxW8> (part 4)

<http://www.youtube.com/watch?v=ppp9Xw54m-M> (part 5)

<http://www.bingcenterforwm.org/media-gallery/343-iwmmf-patient-ed-forum-june-24-26-2011-ask-the-doctor-panel-discussion>



The Bing Center for WM's main website has changed. A fresh, new look has been administered in order to ease the viewer into finding any kind of knowledge on Waldenstrom's macroglobulinemia. Font size can be adjusted, the most current publications are available from our research, and video lectures have been added! Please go to www.bingcenterforwm.org and check it out!

NEW Publications for 2011!



On behalf of the Bing Center for WM, the following publications have just been published within the past couple of months. **All publications** are/will be found on the Bing Center Website at www.wmprogram.org

1. **Long-term follow-up of symptomatic patients with lymphoplasmacytic lymphoma/Waldenstrom's macroglobulinemia treated with the anti-CD52 monoclonal antibody alemtuzumab.** (BLOOD publication 2011)
2. **Maintenance Rituximab is associated with improved clinical outcome in Rituximab naïve patients with Waldenstrom Macroglobulinemia who respond to a Rituximab-containing regimen.** (British Journal of Haematology 2011)
3. **Bendamustine Therapy in Patients with Relapsed or Refractory Waldenstrom's Macroglobulinemia** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)
4. **Fcy Receptor Predictive Genomic Testing and the Treatment of Indolent Non-Hodgkin Lymphoma** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)
5. **Attainment of complete/very good partial response following rituximab-based therapy is an important determinant to progression-free survival, and is impacted by polymorphisms in FCGR3A in Waldenström macroglobulinemia.** (British Journal of Haematology 2011)
6. **Histone deacetylase inhibitors demonstrate significant preclinical activity as single agents, and in combination with bortezomib in Waldenström's macroglobulinemia.** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)
7. **Hepcidin is produced by lymphoplasmacytic cells and is associated with anemia in Waldenström's macroglobulinemia.** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)
8. **Carfilzomib-dependent selective inhibition of the chymotrypsin-like activity of the proteasome leads to antitumor activity in Waldenstrom's Macroglobulinemia.** (Clinical Cancer Research 2011)
9. **Associated malignancies in patients with Waldenström's macroglobulinemia and their kin.** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)
10. **Report from the Sixth International Workshop on Waldenström's Macroglobulinemia.** (Clinical Lymphoma, Myeloma & Leukemia publication 2011)

WM dedicated Websites:

Please go to any of the websites for current and updated information regarding WM

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



A NEW LOOK! We regularly update our Bing Center website in order to keep the content up to date.

- **Focus on Patients, Physicians/Researchers, and Caregivers:** Information that can be used "bench to bedside".
- **About the Bing Center:** Description of the Bing Center, clinic and staff.
- **News & Events:** Announcements for recent and upcoming conferences and support group meetings.
- **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).
- **Bing Center Spotlight (NEW):** Focus on topic of special interest to patients, physicians or caregivers.
- **Media Gallery:** Videos and photos from our conferences and special events.

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.

www.steventreon.com

- **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.

www.wmworkshop.org

A NEW LOOK! This website includes all the abstracts, agenda, photos, and other information from all the International Physician Workshops for WM held from 2000 to the present. The next Physician conference will be held on August 22-26, 2012 in Newport, Rhode Island, USA. For additional updated information on the next Workshop in Newport, Rhode Island, USA, please go to www.wmworkshop.org

To research archival information from our previous six workshops (Venice 2010, Stockholm 2008, Kos 2007, Paris 2004, Athens 2002, and Washington DC 2000), please visit the website.

www.wmsummit.org

International Patient and Physician Summits on WM

March 11-13, 2011 Orlando, FL, USA

OVERVIEW - ORLANDO 2011
FACILITY - ORLANDO 2011
ABSTRACTS - ORLANDO 2011
PRESENTATIONS - ORLANDO 2011
MEDIA GALLERY - ORLANDO 2011
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4th International Patient & Physician Summit on Waldenström's Macroglobulinemia

March 11-13, 2011 Orlando, FL

The 4th International Summit on WM was held March 11-13, 2011 at the [Buena Vista Palace Hotel](#), Walt Disney World Resort, Orlando, FL. Over 300 patients, caregivers, and their families attended this 3 day conference, which included 7 sessions with 23 technical presentations from 17 faculty speakers, including 5 debates, and 6 case presentations. In addition were special guest presentations by Karen Lee Sobol, author of "Twelve Weeks, An Artist's Story of Cancer, Healing, and Hope", and Judith May, president of the [IWMF](#), who gave an overview of this organization's vital role in the continuing education and support of people with Waldenström's Macroglobulinemia.

In addition to the conference sessions was an evening dinner event at the 27Skywalk, and a poolside gala, where patients and family members joined with the faculty to share some good food and conversation in a relaxed atmosphere.

You may review the faculty [biographies](#) and selected [abstracts](#) from the lectures here. You also may download the actual [presentations](#) which are posted as individual slides, as well as [photos](#) from the conference. You may also download the [conference agenda](#), as well as the [faculty directory](#). We hope that this conference has provided an opportunity for patients and caregivers to learn firsthand, from our frontline researchers, the latest in the genetic basis, pathogenesis, and treatment of WM, and enriched each attendee's understanding of this disease.

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

The **2013 Patient and Physician Summit is projected to be held in Boston, MA late Spring/Early Summer. *More details will follow.*** To review: the Fourth International Summit held on March 11-13th, 2010, at the Buena Vista Hotel Resort in Orlando, FL.

- **Faculty:** Photos and biographies of the faculty members who presented at this conference.
- **Abstracts:** Abstracts submitted by the faculty members, on topics 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:** Hundreds of photos taken at the conference sessions, evening events, and other conference-related activities.
- **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 a means for those with Waldenström's macroglobulinemia, their family members, doctors, and others with an interest in the disease to find mutual support and encouragement, to provide information and educational programs that address patients' concerns, and to promote and support research leading to a cure.

For additional information, please contact Sara McKinnie, IWMF Business Office, 3932D Swift Road Sarasota, FL 34231, Tel: (941)927-4963

Email: info@iwmf.com



Autumn Health Tips



Here are some important tips to keep you healthy through the autumn season, and various holidays. It is very important to keep your entire body, mind, and habits fit and active!

Autumn and Allergies!

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.