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Bing Center for Waldenström's Macroglobulinemia Newsletter

June 2010

Dear Patients & Friends-

The June issue of our newsletter contains a variety of information focusing on the most recent added information and changes to our Bing Center websites, poster presentations from the latest ASCO meeting held in Chicago, IL, and Summer-time tips for 2010.

Clinical Trials

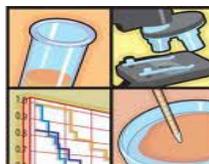
Just to generalize, although there are many definitions of clinical trials, they are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol. ClinicalTrials.gov includes both interventional and observational types of studies. Interventional 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 (Waldenström'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.



American Society of Clinical Oncology (ASCO) 2010 Annual Meeting

The 2010 ASCO Physician Conference was held on June 4th to June 8th, 2010 in Chicago, IL. The American Society of Clinical Oncology (ASCO), www.asco.org, is an annual Conference for Hematologists and Oncologists that offer invaluable benefits, including up-to-date research, therapies, and networking events that allowed physicians to connect with colleagues and interact with leaders in the field in all branches of hematology and oncology, mainly on a clinical level. Overall, the Conference is a great success for the Bing Center for WM. Our six (6) abstract submissions were presented to over 20,000 medical peers from around the world. Our 2010 ASCO abstracts and posters can be found on our main website at www.wmprogram.org/NewsEvents.

The titles of the presentations were:

Guang Yang *The CD20 directed monoclonal antibody GA101 demonstrates more robust activity relative to Rituximab in Waldenstrom's Macroglobulinemia (WM), and may be particularly applicable to those patients expressing FcgRIIIA-158 F/F*

Jake Soumerai *Phase II Study of Alemtuzumab in Lymphoplasmacytic Lymphoma (Waldenstrom's Macroglobulinemia): Long Term Follow-Up of WMCTG trial 02-079.*

Stephen Treon *Clinical characteristics and treatment outcome of disease related peripheral neuropathy in Waldenstrom's Macroglobulinemia (WM)*

Thea Ioakimidis *Maintenance Rituximab is associated with improved clinical outcome in rituximab naïve patients with Waldenstrom's Macroglobulinemia (WM) who respond to a rituximab containing regimen.*

Zachary Hunter *The attainment of CR/VGPR is associated with significantly longer progression free survival in rituximab naïve WM patients undergoing rituximab based therapy, and is predicted by polymorphisms in FcgRIIIA-158.*

Douglas McMillan *Activity of the NEDD8-specific inhibitor MLN 4924 in multiple myeloma and Waldenström's macroglobulinemia, and effect on miRNA expression*

For any questions about the abstracts, please feel free to contact Christopher Patterson at cpatterson1@partners.org and we will be happy to direct you to the author of the presentation.



JUNE 4-8, 2010 | MCCORMICK PLACE | CHICAGO, ILLINOIS

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 ASCO 2010 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. Steve 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 Waldenström's 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 [WM 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 **06.09.10** **Online Registration for the Venice 2010 (IWWM-6) Workshop**

Online registration for IWWM-6 is now operational. To register for this workshop, please visit our [IWWM-6 Online Registration Page](#). This page allows you to register by credit card, using the secure PayPal payment system. You may also register and pay by check by following the steps outlined below. Please report any issues with using our online registration system to our [webmaster](#), or the conference secretariat, [Christopher Patterson](#).

Washington 2000 **06.04.10** **Venice 2010 (IWWM-6) Workshop Registration**

We are now accepting registrations for IWWM-6. We are currently working on an online registration mechanism and expect it to be operational shortly. In the meantime, we are accepting "pre-registration" by email, and payment via postal service. Please follow these steps to register for IWWM-6:

- 1) To "pre-register", send an email to our [Conference Secretariat](#) containing your name and contact information, the names of any guests who will be accompanying you, and any dietary restrictions.
- 2) Conference Registration is \$400(USD) per person this includes all conference sessions, lunches, coffee breaks, and all conference materials. Please make check payable to **The Bing Center for WM**

This website includes the information for the upcoming 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.

www.wmsummit.org

International Patient and Physician Summits on WM

March 10-13, 2011 Orlando, FL, USA

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Welcome to the 4th International Patient & Physician Summit on Waldenström's Macroglobulinemia

March 10-13, 2011 Orlando, FL

The 4th International Summit on WM will be held March 10-13, 2011 at the [Buena Vista Palace Hotel](#), Walt Disney World Resort, Orlando, FL. You may register for this event by downloading and printing the [conference brochure](#) below, and mailing the registration portion, or by going to the [Orlando 2011 Online Registration page](#). More details, including the conference program, will be posted as they become available.

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. Steven 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 Boston 2009 conference program in PDF format](#)

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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 upcoming 2011 Patient and Physician Summit will be held in Orlando, FL from March 11-13th, 2011. Online registration for this conference is now available on the website. More details of this event, including the conference agenda will be posted as they become available.

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

- **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

INTERNATIONAL
WALDENSTROM'S MACROGLOBULINEMIA
FOUNDATION



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.

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Summertime Health Tips



I've done some sleuthing and have come up with some important tips to keep you going this Summer no matter where you live on this planet! It is very important to keep your entire body, mind, and habits fit and active!

Summertime heat can simply be overwhelming. Summer heat can be intense, especially if you live in a muggy, humid area. When temperatures reach record highs, keeping cool isn't just about comfort. High temperatures can result in heat-related illnesses like heat stroke and heat exhaustion with the elderly, children and pregnant women being at a greater risk.

Dehydration is another major health issue. The body sweats in an attempt to keep the body's core temperature stable, but in very high temperatures the body will sweat at a rate higher than fluid can be replaced, creating a dangerous situation. If the humidity is higher, it is more difficult for the body to perspire normally. Here are a few ideas to help you keep cool this summer:

1. **Clothing:** Dress for the heat by wearing loose-fitting clothes, preferably of a light color like white instead of dark-colored clothing. The dark clothing attracts the heat and will leave you hot and steamy. Cotton clothing will keep you cooler than many synthetics. Use a hat to protect your head from the sun when you go out.
2. **Hydration:** As you get hot, your body perspires in an effort to cool itself. Replacing the loss of fluid is vital. It is imperative that you consistently drink plenty of water several times a day. Do not rely on your thirst mechanism as by the time you feel thirsty, you are already slightly dehydrated. The ubiquitous lemon water and coconut water are the ideal summer drinks. Avoid caffeinated beverages or alcohol which will dehydrate your body.
3. **Stay indoors:** The thumb rule to avoiding sunstroke is to avoid exposure to the sun when it is at its zenith. Stay indoors during the hottest part of the day during the summer and avoid outdoor activities in direct sunlight or on hot asphalt surfaces. Spending more time in properly ventilated or air-conditioned place decreases the risk of heat-related illnesses.

4. **Nutrition:** Eat light meals including frequent small meals containing cold fruit or low fat dairy products and avoid hot foods on these hot days. Foods that are heavier on your stomach take a lot of energy to digest which slows down your body's cooling process. By eating chilled foods, salads, fruits, and vegetables, you'll keep your body temperature down. Avoid too much of fried and processed food which will make you lousy and fatty.
5. **Sunscreen:** Apply a sunscreen lotion before leaving your home. Opt for the sunscreen which contains minimum of SPF 15. Sunscreen should be applied liberally, uniformly and thickly to all exposed skin surfaces. Don't forget to protect lips, ears and toes.
6. **Insect protection:** There are many insect infections that are more common in the summer and can cause symptoms. You can use insect repellents and cover your body adequately to prevent mosquito bites.
7. **Protect your eyes:** Sunglasses with UV protection can help enhance the eyes to filter out the sun's damaging rays. Choose sunglasses that block 99 to 100 percent of UV radiation.
8. **Bath often:** Take frequent cool showers or baths. This will help keep your body temperature down. Even better, there's nothing that cools you off better in the summer than a dip in the cool swimming pool. You can also keep a spray bottle filled with water in the refrigerator and use it for a quick refreshing spray to your face after being outdoors.
9. **Hair care:** Keep hair up off the neck, either by cutting it shorter or by twisting it up into a big clip or a ponytail. Massage your hair daily with oil in the night before going to sleep and use mild shampoos for hair wash the following morning.
10. **Rest:** Rest frequently and avoid overexerting yourself. If you feel tired or over-heated, take a nap.

Skin Care in Summer

Summertime can be a bad time for skin. Those warm days can also bring a new host of skincare issues you need to know how to deal with. From UVA rays to pool chlorine, it's important that you are ready and prepared to keep your skin healthy and protected from the elements of summer. Excessive heat during the summer disturbs the critical oil-water balance in the body. Too much of perspiration clogs the pores and exposure to the U.V. rays results in premature aging, wrinkles and sagging of the skin.

1. Drink lots of water throughout the day, not only to replenish moisture lost to the heat and sweat but also to help flush toxins out of the body and keep skin looking clear and lustrous. Herb or spice teas, made with skin-enhancing ingredients, offer added therapeutic benefit. To balance the body, choose cooling herbs and spices such as mint, cardamom and fennel.
2. Eat body-balancing fruits, vegetables and herbs, which supply the skin with essential nutrients and come with free-radical fighting antioxidant properties while they help keep your skin cool. Carrots, lettuce, and leafy greens are good vegetable choices. Sweet juicy fruits such as pears, grapes, watermelon and mangoes both nourish and cleanse. Go easy on spicy or sour foods, especially if you plan to go out and enjoy the sun for the day, to keep your skin from breaking out or getting inflamed. Milk is a cooling, beverage that also supplies nutrients to your skin and helps to keep it from drying out.
3. Do not go out during the hottest parts of the day, between 10 a.m. and 4 p.m. If you exercise outdoors, do it early in the morning. Wear sunscreen, lip protection, sunglasses and a broad-brimmed hat when you go out-exposure to the sun can age skin very rapidly.

Have a Wonderful Summer !

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.