

Steven P. Treon MD, Ph.D  
Center Director  
Bing Center for WM  
Dana Farber Cancer Institute  
44 Binney Street M548  
Boston, MA 02115  
Tel: 617-632-2681



Christopher J. Patterson  
Academic and Research Director  
Bing Center for WM  
Dana Farber Cancer Institute  
44 Binney Street M548  
Boston, MA 02115  
Tel: 617-632-6285

## Bing Center for Waldenström's Macroglobulinemia Newsletter

**February 2011**

Dear Patients & Friends-

Welcome to 2011!~ This issue of our newsletter contains a variety of information including the upcoming 4th International Patient-Physician Summit, Orlando, FL 2011, updates on 6 dedicated websites for WM, ASH 2010 submissions, Winter Health Tips on Flu & Allergies, and a very special excerpt on a very special author, artist, philanthropist, and WMer dedicated to the advocacy for WM, Mrs. Karen Lee Sobol.

### **LAST CHANCE TO ATTEND**

**The 4<sup>th</sup> International  
Patient-Physician Summit on WM**

**Orlando, Florida March 11-13, 2011**



This event will be a three-day (3) event and will have 20+ international physicians and scientists speaking on many aspects of WM.

Topics include a whole new section for new WM patients such as a Sessions on the "Diagnosis & Predispositions of WM". Further Sessions include current Genetic Insights, Treatment Options & Strategies, (the very popular) Patient Case Presentations, and a new event; "Hot Topic Debates; Pro's and Con's of Treatment challenges".

**Registration is FREE!** Spaces are **75%** full and we would love to give you the most updated information on Waldenström's! An electronic version of the brochure can be found on the website at [www.wmsummit.org](http://www.wmsummit.org)

The Summit is lectured in a Patient-Caregiver friendly format, so all lectures and Q&A are on a non-Physician level of understanding! For more information, please go to [www.wmsummit.org](http://www.wmsummit.org) for hotel, evening events, and program agenda.



*Twelve Weeks*  
*An Artist's Story of Cancer, Healing, and Hope*  
by Karen Lee Sobol

*~Very healthy for most of her life, at age fifty six Karen Lee Sobol received a shocking diagnosis. A rare incurable blood cancer raged through her. Unwilling to accept conventional chemotherapy, she chose to enroll in a clinical trial. For twelve weeks, every Monday, Wednesday and Friday, she received an experimental biology-based drug. Enlisting traditional and Holistic healing techniques to supplement aggressive medical treatment, over time Karen Lee became cancer-free. Her experience marks a breakthrough in medical science. With compassion and humor, Twelve Weeks takes a reader inside the world of cancer, and the people, thoughts, and emotions that led to Karen lee's decision to believe in her recovery and return to good health. With hope in her heart, she illustrates her story with her art. Useful as a medical, emotional and spiritual guide for people experiencing cancer, treating it, or seeking to cure it, Twelve Weeks offers both information and inspiration~*

Karen Lee Sobol is a painter, printmaker and sculptor. As an advocate for the Bing Center for Waldenstrom's macroglobulinemia at the Dana Farber Cancer Institute, she supports cancer education and research.

Karen Lee Sobol, a pioneer in educating many through her feelings of art and writing, will be at the 4<sup>th</sup> International Patient-Physician Summit this coming March in Orlando, Florida to reveal her book to the attendees, give a brief guest talk, and answer any questions. For more information about "Twelve Weeks—An Artist's Story of Cancer, Healing, and Hope", please join the dedicated Face book page, or contact Chris Patterson on how to obtain the book. ([cpatterson1@partners.org](mailto:cpatterson1@partners.org)).



<http://www.hematology.org/Meetings/Annual-Meeting/>

### **American Society of Hematology (ASH) 2010 Annual Meeting**

The 2010 ASH Physician Conference was held from December 3<sup>rd</sup> to December 8<sup>th</sup>, 2010 in Orlando, Florida. The American Society of Hematology (ASH), [www.ash.org](http://www.ash.org), is an annual Conference for Hematologists and Oncologists that offer invaluable benefits, including up-to-date research, therapies, and networking events that allow physicians to connect with colleagues and interact with leaders in the field in all branches of hematology and oncology. Overall, the Conference is always a great success for the Bing Center for WM. Our seven (7) abstract submissions were presented to over 20,000 medical peers from around the world. Our 2010 ASH abstracts and posters can be downloaded from our main website at [www.wmprogram.org/NewsEvents](http://www.wmprogram.org/NewsEvents).

#### ***The titles of the presentations were:***

**Guang Yang** The Rituximab and IVIG Related IgM Flare In Waldenstrom's Macroglobulinemia Is Associated with Monocytic Activation of FcgrIIa Signaling, and Triggering of IL-6 Release by the PI3K/AKT and MAPK Pathways

**Lian Xu** Involvement of Lipogenic Pathway In 5-Azacytidine-Induced Cytotoxicity in Waldenstrom's Macroglobulinemia

**Jingrui Jiang** Microarray Analysis of the Peripheral Monocytes from Waldenstrom's Macroglobulinemia Patients Reveals a Distinct Gene Expression Profile

**Zachary Hunter** Aberrant Expression of Regulatory miRNAs and Transcripts for IRS-PI3K Growth and Survival Signaling in Waldenstrom's Macroglobulinemia

**Christina Hanzis** Associated Malignancies among Patients and Kin with Waldenstrom's Macroglobulinemia

**Megan Lewicki** Comprehensive Assessment of Cytokines and Chemokines in Patients with Waldenstrom's Macroglobulinemia Reveals a Distinct Profile with Pathobiological and Clinical Relevance

**Yangsheng Zhou** Involvement of Ets Factor Spi-B and Id2 in Waldenstrom's Macroglobulinemia

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

## WM dedicated Websites:

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

[www.wmctg.org](http://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](http://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. Stay tuned as posters for the upcoming Ash 2010 conference will be posted soon!
- **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).

The official website of Dr. Steven Treon, its main focus is on Dr. Treon's research of WM. Constant updates have being made to the Publications and Media sections.

- **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.

**A NEW LOOK!** This website includes all the abstracts, agenda, photos, and other information from the Sixth International Workshop for WM held in Venice, Italy. The Physician conference was held on October 6-10, 2010 along with the IWMF patient-physician forum being held on the final day of the conference. For additional updated information on the IWMF forum in Venice, Italy, please go to [www.iwmf.com](http://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 11-13<sup>th</sup>, 2011**. Registration and details of the event are posted.

[www.wmsummit.org](http://www.wmsummit.org)



To review: the 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 10<sup>th</sup> 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](http://www.iwmf.com)



The IWMF, International Waldenstrom'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](mailto:info@iwmf.com)

## Winter Health Tips



### 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.

### FLU Season is here.... To vaccinate or not to vaccinate???

Flu season is approaching, as are all of the radio commercials reminding folks to get vaccinated. Please remember, that anyone diagnosed with WM, an indolent lymphoma, must avoid \*live\* vaccinations. This would include any of the nasal-spray versions of the flu vaccine. As a general rule, clinicians believe that WM patients should be vaccinated against influenza. Keep in mind, that each case is individual. There are some reasons, such as an allergy to eggs, for people to not receive the vaccine. Anecdotally, we have seen temporary rises in IgM following vaccination. However, this does not seem to be permanent, and is not a reason to avoid the flu vaccine.

As always, the best treatment is prevention. Keep in mind these [six helpful hints:](#)

- 1. Avoid close contact.** Avoid close contact with people who are sick. When you are sick, keep your distance from others to protect them from getting sick too.
- 2. Stay home when you are sick.** If possible, stay home from work, school, and errands when you are sick. You will help prevent others from catching your illness.
- 3. Cover your mouth and nose.** Cover your mouth and nose with a tissue when coughing or sneezing. It may prevent those around you from getting sick.
- 4. Clean your hands.** Washing your hands often will help protect you from germs.
- 5. Avoid touching your eyes, nose or mouth.** Germs are often spread when a person touches something that is contaminated with germs and then touches his or her eyes, nose, or mouth.
- 6. Practice other good health habits.** Get plenty of sleep, be physically active, manage your stress, drink plenty of fluids, and eat nutritious food.

**Contributions or Pledge Donors  
for the Bing Center for Waldenstrom's Macroglobulinemia**



*Valentine's Day* is coming and what better way to show LOVE than with a gift of contribution to the Bing Center for WM!! There are a number of ways to have an impact on the innovative investigations in WM, which have, as their ultimate goal, the development of new and effective treatments for patients as rapidly as possible. A gift of *any* size makes a difference.

For those wishing to make donations, Company-gift matching, stock donations, or just have a little extra pocket money from the holidays, please contact Chris Patterson at the Bing Center for WM at 617.632.6285 or reach him at [cpatterson1@partners.org](mailto:cpatterson1@partners.org)

Dana-Farber also offers the following naming opportunities for those wishing to make a larger pledge to the Bing Center for Waldenstrom's macroglobulinemia, payable over 3-5 years, unless otherwise noted:

\$100,000 - \$5M+ Research Fund in WM – Makes resources immediately available for innovative investigations, taking them to the “next level.”

\$150,000+ Term Fellowship in WM – Enables an outstanding physician-scientist to work in the Bing Center's laboratories for 2 years (Pledge is payable over 2 years)

\$1,000,000+ Endowed Fellowship – Establishes, in perpetuity, a fellowship for the Bing Center's laboratories

For further information on these and other naming opportunities, please contact Sophia Monaghan in the Development Office at 617 632 4055.

**Have a Safe and Healthy Winter!**



*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.*