NEWSLETTER

Bing Center for WALDENSTRÖM'S MACROGLOBULINEMIA

Research • Treatment • Care

November 2011

Dear Patients & Friends-

This issue of our newsletter contains a variety of information on our **8** dedicated website updates, ASH 2011 submissions, upcoming Treon-lectured support group meetings for January 2012, Visiting Professor Highlight, Winter Health Tips on Flu & Allergies, and a survey which will help our Center give us more input and direction for Physician Advocacy.

Below are Highlighted events listed for January 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.

January (SAVE THE DATES)

14th, Southern Florida Patient-Physician Forum, Hollywood, Florida For those who are in the area and/or are interested in attending the Southern Florida Patient-Physician Forum, there will be 4-5 physicians attending and presenting on WM and/ or its correlations to the disease. Further details will be sent out soon.

21st- Dallas, Texas The Dallas, TX Support Group WM lecture will be held on January 21st at the Baylor Sammons Cancer Institute. Further details will be sent out soon.

29th- Boston, Massachusetts The New England Support Group and the Bing Center for WM will be holding a Physician Lecture on the Updates and Advancements in WM. The lecture will be given by Dr Treon (followed by Q&A) and held in the Jimmy Fund Auditorium at the Dana Farber Cancer Institute, Boston, MA. To register, please contact Chris Patterson at cpatterson1@partners.org

American Society of Hematology (ASH)
2011 Annual Meeting

The 2010 ASH Physician Conference will be held from December 10th to December 13th, 2011 in San Diego, California. The American Society of Hematology (ASH), 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 (8) abstract submissions will be presented to over 20,000 medical peers from around the world. Our 2011 ASH abstracts and posters will be found on our main website within the next month at www.wmprogram.org/NewsEvents.

Steven Treon MD PhD (ORAL PRESENTATION) Whole Genome Sequencing Reveals a Widely Expressed Mutation (MYD88 L265P) with Oncogenic Activity in Waldenstrom's Macroglobulinemia

Guang Yang MD (ORAL PRESENTATION) Disruption of MYD88 Pathway Signaling Leads to Loss of Constitutive IRAK1, NF-kappa beta and JAK/STAT Signaling and Induces Apoptosis of Cells Expressing the MYD88 L265P Mutation in Waldenstrom's Macroglobulinemia

Yangsheng Zhou (ORAL PRESENTATION) Aberrant Expression of Oct-2, Spi-B, and Id2/Id1 Is Associated with Repression of Plasma Cell Differentiation in Waldenstrom's Macroglobulinemia

Zachary Hunter (ORAL PRESENTATION) Whole-Genome Sequencing Results From 30 Patients with Waldenstrom's Macroglobulinemia

Lian Xu (ORAL PRESENTATION) A Somatic Variant in MYD88 (L265P) Revealed by Whole Genome Sequencing Differentiates Lymphoplasmacytic Lymphoma From Marginal Zone Lymphomas

Yang Cao MD
(POSTER PRESENTATION 1) MicroRNA-21 and -155 Are Induced by a Widely Expressed Mutation in MyD88 (L265P) in Waldenstrom's Macroglobulinemia

Christina Tripsas
(POSTER PRESENTATION 1) Prospective, Multicenter Study of the MTOR Inhibitor Everolimus (RAD001) As Primary Therapy in Waldenstrom's Macroglobulinemia

(POSTER PRESENTATION 2) Treatment with a Bortezomib-Containing Regimen Is Associated with Better Therapeutic Outcomes in Patients with Waldenstrom's Macroglobulinemia Who Have Familial Disease Predisposition

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

December 10-13, 2011 | SAN DIEGO CONVENTION CTR | SAN DIEGO CALIFORNIA

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

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 IWMF 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=QNLeN9DHDbI (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-iwmf-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!

WM dedicated Websites:

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

www.wmctg.org

ADDITIONAL LOCATIONS HAVE BEEN ADDED! 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 17 USA-based physician members of the WMCTG and their locations.
- **Physicians (Int'l)**: List of the 7 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 Waldenstrom'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.

www.stevenptreon.com

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 Waldenstrom's Macroglobulinemia. Dr. Treon co-authored this paper with Dr. Giampaolo Merlini. A biography of Dr. Jan Gosta Waldenstrom 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

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. **(ONLY 9 sets left!)**
- **Contact Us**: An online form where comments or questions may be submitted to the conference organizers.

www.ewmnetwork.eu

EWM network is an umbrella organization for European WM patient support groups or patient support organizations.

EWM network was initiated in 2008 by the Dutch MM&WM Patient Association (CMWP), The Netherlands and is registered as a not-for-profit organization under Dutch Law.

EWM network aims to represent the interests of WM patients on a European level. It is an organization run by patients and their relatives for patients ("Patients for Patients").

www.wmsupportgroup.org.uk

The Waldenstrom's Macroglobulinemia (WM) United Kingdom (UK) Support Group was officially established in 2000. They are a non-profit organization created to support those suffering from WM as well as their family and friends in UK and Eire.

Their support group is also an affiliated member of the European WM Network, (EWM network) who are members of the European Cancer Patient Coalition, (ECPC) and European Organization for Rare Diseases (EURORDIS). Their aim is to collectively represent all WM patients' interests at a European level. This way, WM patients are given a voice at European health institutions and in European health politics. Hence their motto "Patients for Patients"

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. It mission is to provide a means for those with Waldenstrom'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

Visiting Professor Program
At the Bing Center for WM

Every year, the Bing Center for WM at the Dana Farber Cancer Institute (DFCI) hosts a Visiting Professorship program in the Spring and the Autumn. The program welcomes well-known medical leaders from their Institutes or Centers to spend a week in shadowing the clinicians and learn what the Bing Center has done for patient care, research, and patient advocacy for WM for their own countries. The program also structures the opportunities to learn the aspects of DFCI's multiple myeloma and lymphoma programs as well.

In the beginning of November, a milestone was laid whereas we were visited by two physicians from Tallinn, Estonia. Dr Naame is the Head of the Center of Hematology at the North Estonia Medical Center in Tallinn. Dr Gorjatsev is a Lead Hematologist at the North Estonia Medical Center in Tallinn and was awarded an education grant from the Estonian government specifically to visit us at the DFCI. As a result of their visitation, their observations and education have now developed a foundation for collaborating with us and their WM, multiple myeloma, and lymphoma patients. As of next April, Dr Treon has been invited to be a Key Speaker at their Baltic Hematology Conference (which encompasses 5 Eastern European countries) on WM, and for me to organize a structure for an Eastern European WM Patient Awareness group during their Conference on WM. This is a welcoming and exciting event.

For those who are interested in geography, Estonia is on the north-eastern edge of the European Union, bordering Russia and Latvia. Estonia was occupied by the Soviets for decades but Estonia sees itself as more influenced by Nordic tastes and traditions - Scandinavia with a twist. Overall highlights are: the medieval capital, Tallinn, the fantastic landscape and forests, and is second only to Ireland in Europe when it comes to folkloric history, stories, legends and songs. For more information, go to www.visitestonia.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 coming….. 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.

End of the Year Contributions or Pledge Donors
to the Bing Center for Waldenstrom's Macroglobulinemia

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 year, please contact Chris Patterson at the Bing Center for WM at 617.632.6285 or reach him at 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 Holiday Season!

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.