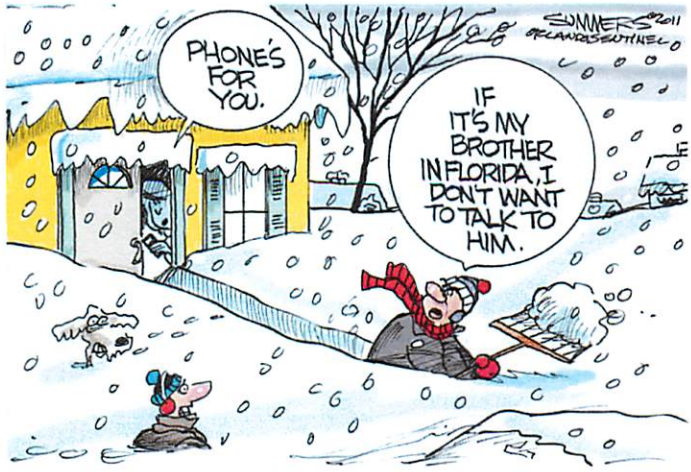
NEWSLETTER

Bing Center for WALDENSTRÖM'S MACROGLOBULINEMIA

Research • Treatment • Care

January 2013



Happy Healthy New Year!

Dear Patients & Friends-

Since our last Newsletter, there has been alot of activity with the Bing Center for WM. In August 2012, we conducted our 7th successful International Workshop on WM and expanded with a Symposium on Multiple myeloma, a multitude of global publications were produced including the *"MYD 88 L265P"* New England Journal publication in December, and most recently, the creation of a web community chat room for Wm'ers brought to you by Dana Farber Cancer Institute and *Cancer Connect*.

Aside from our spotlight topics, a variety of information on our **9** dedicated website updates, upcoming WM meetings, and Insights on the 2013 Flu Outbreak have been included.

Below are Highlighted events listed for the next couple of months. 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.

March (SAVE THE DATES)

17th, March- London, England The WMUK will be holding a physician-patient meeting where leading International and UK WM physicians meet with patients and Caregivers to discuss the very latest treatments and research within their countries. Additional information and the agenda can be found on www.bingcenterforwm.org or you can contact www.wmuk.org.uk for registration or questions. Dr. Robert Kyle will be the Keynote Speaker at this meeting.

May (SAVE THE DATES)

17th to 19th May, San Diego, CA IWMF's annual Educational Forum is a unique opportunity for patients and caregivers to learn from specialists in Waldenstrom's macroglobulinemia (WM) who are involved in many areas of clinical practice and research. Held in a different part of the United States every year, the "Ed Forum" offers something for everyone, no matter what your experience or level of knowledge. The IWMF will be holding their 2013 annual Education Forum at the Westin San Diego Hotel. The agenda is currently in process and for more information and/or to make hotel accommodations, please go to http://www.iwmf.com/services/ed-forum.aspx

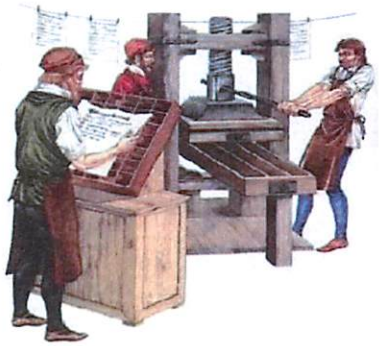
In order for many of our WMer's to see Dr Treon & Dr Hunter's lecture, we decided to have the two videos posted to YouTube. Both lectures are both from the IWWM-8 Workshop from Newport, RI held last August 2012. Each video can be found by accessing the link below or by going to the (www.bingcenterforwm.org) website where you will find a YouTube link at the top of the webpage.

Dr Treon: **Workshop Review Newport 2012**

Dr Hunter: **Revelation of MYD88 L265P as a Novel Mutation in WM**

http://www.youtube.com/user/BingCenterForWM?feature=plcp

NEW Publications List from 2012-13!



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

1. ***Vorinostat induced cellular stress disrupts the p38 mitogen activated protein kinase and extracellular signal regulated kinase pathways leading to apoptosis in Waldenstrom macroglobulinemia cells.*** (Leukemia-Lymphoma publication 2011)

2. ***Matrix metalloproteinase-8 is over expressed in Waldenström macroglobulinemia cells, and specific inhibition of this metalloproteinase blocks release of soluble CD27.*** (Clin Lymphoma Myeloma publication 2011)

3. ***Family History of non-hematologic cancers among Waldenström macroglobulinemia patients: a preliminary study*** (Cancer Epidemiology publication 2012)

4. ***MYD88 L265P somatic mutation in Waldenstrom's macroglobulinemia (New England Journal of Medicine publication 2012)***

5. ***A multicenter phase II study of single-agent enzastaurin in previously treated Waldenström macroglobulinemia*** (Clin Cancer Research publication 2012)

6. ***Waldenstrom's macroglobulinemia/lymphoplasmacytic lymphoma version 2.2013*** (Journal Nat'l Comprehensive Cancer Network, publication 2012)

7. ***Mechanisms of Activity of the TORC1 Inhibitor Everolimus in Waldenström macroglobulinemia*** (Clinical Cancer Research publication 2012)

8. ***Familial disease predisposition impacts treatment outcome in patients with Waldenström macroglobulinemia*** (Clin Lymphoma Myeloma publication 2012)

9. ***Response Assessment in Waldenström macroglobulinemia: update from the VIth International Workshop, Stockholm Sweden*** (Br Journal of Haematology, publication 2012)

10. ***Results of the phase II trial of single agent histone deacetylase inhibitor panobinostat in patients with relapsed/refractory Waldenström macroglobulinemia*** (Blood publication 2013)

11. ***MYD88 L265P in Waldenstrom's macroglobulinemia, IgM Monoclonal Gammopathy, and other B-cell Lymphoproliferative Disorders using Conventional and Quantitative Allele-specific PCR*** (Blood publication 2013)

A new national online community provides support for individuals affected by Waldenström's Macroglobulinemia.

Boston, MA & Sun Valley, ID – OMNI Health Media (OMNI) announces the launch of an online community for individuals affected by Waldenström's Macroglobulinemia, a rare, slow-growing type of non-Hodgkin's lymphoma. Experts from Dana-Farber Cancer Institute will moderate the community, which will provide patients and their loved ones with welcome information and support. This community will be part of the national CancerConnect.com initiative.

I'd like to invite you to join the Waldenström's Macroglobulinemia (WM) national community, brought to you by Dana-Farber Cancer Institute and Cancer Connect.

This community connects you with many others from around the world affected by WM for support, guidance, and information about the disease and its related issues. You can share your experiences and knowledge, ask questions, and learn from others who are coping with WM. This community is moderated by Dana-Farber staff with extensive expertise in Waldenström's Macroglobulinemia.

Being the moderator of this online community room is a very exciting and great way to assist and guide you with your questions, provide you with direction, and take this disease's progress to a new level. Aside from the WM community room, there are other community rooms available at the same site for those who have secondary cancers or who are just inquisitive of other diseases. Looking forward to seeing you in the Community room!

If you would like to join this community, please follow these steps to register:

- Click here: http://cancerconnect.com/danafarber to access the Dana-Farber Welcome page, then click **Join now**.
- Enter your user name, e-mail address, and password, and click **Register**.
- Once you have registered, on the main Dana-Farber Cancer Connect Community page, you can access the Waldenström's community one of two ways, either:
    - Scroll down the right side of the page, under **National group members**, and click **Waldenström's**, or
    - Click this link after you have registered or logged in:

http://cancerconnect.com/group/waldenstrom-macroglobulinemia

Cancer Connect allows individuals to interact in a HIPPA-compliant, confidential, safe, and secure environment. As part of this program, members of the community can also participate in more than sixty disease-specific national communities. Cancer-specific groups are available, as well as groups focused on care giving, health and wellness, clinical trials, insurance, nutrition and survivorship, providing support for anyone affected by a diagnosis of cancer.

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

6 months Away~ 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 will not be held this year**. ***More details will follow.*** To review: the Fourth International Summit was held on March 11-13th, 2010, at the Buena Vista Hotel Resort in Orlando, FL. Program video is available online.

- **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

EWMnetwork

European Waldenström's Macroglobulinemia network

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").

Waldenström France

The Waldenstrom's France associate was officially established in 2009. Their website has just been released in hopes to benefit all French-speaking patients, caregivers, physicians, and medical specialists and to guide them properly in the knowledge of WM on a clinical, research, and patient-support direction. Currently, the association has a very active Talk list for all Francophone members (more than 153) from Canada, Belgium, Brazil, Switzerland, North Africa and France. Please visit their website for more information http://portail.waldenstromfrance.org, become a community member or contact the president of the association of WM France, Michel Houche at houchemichel@wanadoo.fr with any questions.

www.wmsupportgroup.org.uk

WM

Waldenström's Macroglobulinaemia
UK Support Group

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 is 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". The next WMUK Patient forum is being held on March 17th, 2013. For more details, please visit their website.

www.iwmf.com

IWMF

International Waldenstrom's Macroglobulinemia Foundation

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, 6144 Clark Center Avenue, Sarasota FL 34238 Tel: (941)927-4963
Email: info@iwmf.com

TOD Topic of Discussion:

Flu Outbreak of 2013

Flu Myths vs. Flu Facts

Does a flu shot cause the flu? Do healthy people need a shot?

Here are the answers to some myths

Flu Myth #1 A Flu Shot Causes the Flu

No, a flu shot cannot cause flu illness. The influenza viruses contained in a flu shot are inactivated (killed), which means they cannot cause infection. Flu vaccine manufacturers kill the viruses used in the vaccine during the process of making vaccine, and batches of flu vaccine are tested to make sure they are safe. In randomized, blind studies, where some people get flu shots and others get salt-water shots, the only differences in symptoms was increased soreness in the arm and redness at the injection site among people who received the flu vaccine.

Flu Myth #2 The 'Stomach Flu' is a Form of the Flu

Many people use the term "stomach flu" to describe illnesses with nausea, vomiting or diarrhea. These symptoms can be caused by many different viruses, bacteria or even parasites. While vomiting, diarrhea, and being nauseous or "sick to your stomach" can sometimes be related to the flu — more commonly in children than adults — these problems are rarely the main symptoms of influenza. **The flu is a respiratory disease and not a stomach or intestinal disease.**

Flu Myth #3 The Flu Shot is Dangerous

Over the last 50 years, seasonal flu vaccines have had very good safety track records. Over the years, hundreds of millions of Americans have received seasonal flu vaccines. Every year the same methodical process is used to make vaccine to protect against the different flu strains. Vaccination is the gold standard of care recommended by the U.S. Centers for Disease Control and Prevention (CDC), safe to receive and the most effective way to protect against the flu and spread of infection.

Flu Myth #4 Younger, Healthier People Don't Need a Flu Shot

Everyone who is at least 6 months of age should get a flu vaccine this season as everyone is at risk of infection. This includes health care workers, pregnant women, people 65 and older, people who have certain medical conditions like asthma, diabetes and chronic lung disease, and people who live with or care for others who are high risk of developing serious complications.

Flu Myth #5 Antibiotics will treat the Flu

Because flu is caused by viruses and not by bacteria, antibiotics aren't effective. Antiviral drugs can treat flu illness. They can make people feel better and get better sooner and may prevent serious flu complications, like pneumonia, for example, that can lead to hospitalization and even death. These drugs are different from antibiotics, but they also need to be prescribed by a doctor. They work best when started during the first 2 days of illness. It's very important that antiviral drugs be used early to treat the flu in people who are very sick (for example people who are in the hospital) or people who are at greater risk of having serious flu complications. Other people with flu illness may also benefit from taking antiviral drugs and should see their physician.

Myth #6 The Vaccine Does Not Work, Why get it

The flu vaccine is the single best way to prevent the flu, and vaccination is the main tool used to protect people from influenza. But protection is never 100 percent, and some people can still get the flu after being vaccinated. How well the flu vaccine works (or its ability to prevent influenza illness) can range widely depending on who is being vaccinated. In general, the flu vaccine works best among young healthy adults and older children. Some older people and people with certain chronic illnesses might develop less immunity than healthy young adults after vaccination. However, even for these high-risk individuals, the flu vaccine still can provide protection against getting severe complications from the flu. While determining how well a flu vaccine works is challenging, in general, recent studies have supported the conclusion that influenza vaccination benefits public health, especially when the viruses in the vaccine and circulating viruses are well-matched.

Myth #7 It's Too Early to Receive a Flu Shot

Flu seasons are unpredictable. They can begin early in the fall and last late into the spring. As long as flu season isn't over, it's not too late to get vaccinated, even during the winter. Getting a flu vaccine is the best way to protect yourself and your family. **The flu vaccine offers protection all season long.**

Winter Health Tips

Winter Allergies

Think that allergies aren't a problem during the winter? Think again. Some areas of the country experience their worst allergy season during the wintertime, when mountain cedar pollinates. And even when the plants outside aren't pollinating, other triggers still exist to make your nose congested and runny. From outdoor mold to irritants such as cold and windy weather, there are a number of non-pollen sources of wintertime nasal symptoms. In addition, cold temperatures can lead to hives, which is called cold urticaria.

Winter Pollen Allergies Mountain cedar is a type of juniper tree found mainly in South and Central Texas that pollinates in the winter, from December through March. In the areas where it grows, it is usually the only major pollen present during the wintertime. Mountain cedar is a major cause of hay fever, and people who suffer from this form of pollen allergy typically refer to it as "cedar fever." Learn more about mountain cedar allergy.

Runny Noses in Cold Weather As the weather starts to turn cold and crisp around the country, people are packing their pockets with tissues to combat their runny noses. But this usually isn't due to allergies -- rather, it's caused by vasomotor rhinitis. This non-allergic form of rhinitis may result in a runny nose, post-nasal drip and/or nasal congestion. It is caused by a number of triggers, including temperature changes, windy weather, and changes in humidity, as well as strong odors, perfumes and smoke. Learn more about the causes and treatment of a runny nose in cold weather.

Mold Allergies in the Winter Airborne molds are well-known causes of allergic rhinitis and asthma symptoms, and can be present outdoors and indoors. In colder climates, molds can be found in the outdoor air starting in the late winter to early spring, especially during the rainy season. While indoor molds can occur year round and are dependent on moisture levels in the home, indoor mold levels are higher when outdoor mold levels are higher. Therefore, a common source of indoor mold is from the outside environment, although can also be from indoor mold contamination. Learn more about mold allergy.

Hives in the Cold Cold urticaria is a form of physical urticaria that is characterized by the development of hives and swelling with cold exposure. A variety of cold triggers can cause symptoms in people with this syndrome, including cold weather, cold food and drinks, and swimming in cold water. Learn more about the causes and types of cold urticaria, as well as the treatments available.

See you in March!