



Bing Center for WALDENSTRÖM'S MACROGLOBULINEMIA

Research • Treatment • Care

February 2012



Dear Patients & Friends-

This issue of our newsletter contains a variety of information on our [9](#) dedicated website updates, upcoming Treon-lectured support group meetings for March-June 2012, MYD-88- What is it?, Topic of Discussion: Food Poisoning, and Tips on Winter Allergies.

Below are Highlighted events listed for March 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.

5th-February Boston, Massachusetts The New England Support Group and the Bing Center for WM held a Physician Lecture on the Updates and Advancements in WM. The lecture was given by Dr Treon (followed by Q&A). If you wish to see the 1-½ hour Lecture, please go to the specific link provided.

Link to the presentation: <http://video.dfcionline.org/accordent/Waldenstroms/>

If you wish to have a DVD version of this presentation, please contact Chris Patterson at cpatterson1@partners.org

March (SAVE THE DATES)

3rd, March- Sarasota, Florida The IWMF will be hosting a SW Florida Support Group meeting at the Doctors Hospital in Sarasota, FL. Dr. Treon will be lecturing at 11am. Additional information can be found on www.bingcenterforwm.org or you can contact Herb & Marge Kallman at 239.466.6911 or margerina@aol.com for attendance.

11th, 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. Treon will be the Keynote Speaker at this meeting.

31st, March- Needham, Massachusetts The Lymphoma Research Foundation will be holding their Northeast Lymphoma Workshop from 7:30am-2:30pm. It's a great Workshop to learn about your specific type of lymphoma, hear a variety of presentations, and meet other people with WM. Dr. Treon will be lecturing on WM at 11am that day. To register call 800.500.9976 or mspellman@lymphoma.org

May (SAVE THE DATES)

19th- May Atlanta, Georgia The Atlanta, Georgia Support Group in collaboration with the Leukemia & Lymphoma Society will be holding their Spring meeting on Saturday, May 19. Other group members from South Carolina, Tennessee, and Alabama are welcome to attend. Dr. Steven Treon from the Bing Center for WM, Dana Farber Cancer Institute, will be presenting the latest WM research and treatments. Please save the date and contact Mal & Judy Roseman at 770-392-1255 or malroseman@comcast.net if you plan to attend. More details as to the location and times will be announced. Your doctors are welcome to attend.

June (SAVE THE DATES)

1st-3rd- June, Philadelphia, Pennsylvania 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 2012 annual Education Forum at the Philadelphia Airport Marriott. 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>

MYD88-one of three billion letters in the human genetic code – as the leading culprit in Waldenström's, and a prime target for new therapies against the disease.

To recap some background for new patients, Waldenström's macroglobulinemia is a slow-growing form of non-Hodgkin lymphoma that originates in white blood cells known as B lymphocytes. When abnormal B cells begin to multiply out of control, they produce excessive amounts of a protein called monoclonal immunoglobulin, which causes the blood to thicken and flow less smoothly. In some patients, the disease produces no major symptoms; in others, problems can include weakness, fatigue, excessive bleeding, and weight loss. In severe cases, vision and neurological problems can occur. Approximately 2,000 to 3,000 people are diagnosed with Waldenström's each year in the United States; it is more common in men than women, more prevalent in people of Ashkenazi (Eastern European Jewish) descent, and arises more often in older people than young.

Since the disease was first described 70 years ago, all previous efforts to track down a genetic cause have been fruitless, Dr. Treon remarks. For the current research, Dr. Treon and his colleagues conducted whole genome sequencing of tumor cells and normal cells from 30 patients with Waldenström's. In collaboration with Complete Genomics of Mountain View, Calif., researchers "lined up" the sequences of the tumor and non-tumor cells to identify differences. Ninety percent of the tumor cells had a point mutation in the gene MYD88. MYD88 is a protein which, in humans, is encoded by the *MYD88* gene. "In subsequent experiments, when we treated the tumor cells with drugs that target the pathway activated by the mutated gene, the cells underwent apoptosis, or programmed cell death.

The discovery was made by sequencing the genome of tumor cells in Waldenström's patients, reading the cells' DNA letter by letter, and seeing where it differed from that of the patients' normal cells. In a further in-depth description, "The mutation causes the cells to produce a distorted protein, which switches on the IRAK complex pathway leading to activation of NF-κB, a protein that is essential for the growth and survival of Waldenström's tumor cells," Treon comments. "When we shut down the pathway by blocking the abnormal protein with drug molecules, the tumor cells entered apoptosis." Equally important, the tested molecules had no adverse effect on normal cells. These results suggest that new, effective treatments that target the tumor cells directly are now possible for people with the disease."

Drugs that block the abnormal protein or other proteins in the NF-κB pathway could, theoretically, short-circuit the disease process in many patients. Some of these drugs already exist with Pharmaceutical companies, having been developed for other conditions. Treon and his colleagues are currently working to develop specific drugs and are testing them in experimental models. Patient clinical trials are most likely to begin within the next 1 ½ to 2 years at the Bing Center for WM.

**some excerpts of this content were taken from the www.bingcenterforwm.org website.

[NEW Waldenstrom's Website](#)
[for French speaking Patients, Caregivers and their physicians!](#)



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.

[Additional 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 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.



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.



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 Waldenström'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 IWWMF, 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, IWWMF Business Office, 3932D Swift Road
Sarasota, FL 34231, Tel: (941)927-4963
Email: info@iwmf.com

TOD Topic of Discussion:

Food Poisoning



I was pondering this past week as to what topic should be brought to discussion and, unfortunately, food poisoning fell into my hands (figuratively, of course). Just last night I was called over to my in-laws carrying a bag of Gatorade and Imodium (Loperamide) due to an attack of food poisoning from either take-out food and/or past expiration dates. (Final determination of its whereabouts is still out with the jury). So, I decided that this was an important topic, did some research, and bring to your attention the awareness of Listeria poisoning.

The Times said that the "waste not, want not" ethos of the post-war period could be responsible for the increase in the number of cases of food poisoning. The Daily Mail said that rising food prices and fixed incomes meant that pensioners were keeping food for longer than they should.

The news reports are based on information from The Food Standards Agency (FSA), which says that people aged 60 and over are more likely than younger people to take risks with use-by dates. The FSA said that eating food past its use-by date increases the risk of food poisoning from listeria. There has been a recent surge in the number of cases of listeria, many of which have been in the over-60s, a high-risk group for the potentially deadly bug.

Dr Andrew Wadge, Chief Scientist at the FSA, said, "There are some really simple steps people can take to prevent getting ill in the first place: be aware that 'use by' dates indicate how long food will remain safe, and then make sure you stick to them; always follow the storage instructions on the label; and make sure your fridge is cold enough – between 0°C and 5°C is ideal."

What is Listeria? Listeria (full name *Listeria monocytogenes*) is a type of bacteria that can cause food poisoning when eaten. It can live and grow in a wide range of foods, in particular chilled ready-to-eat foods such as packaged sandwiches, butter, cooked sliced meats, smoked salmon, certain soft cheeses and pâté. Listeria is killed by pasteurization and cooking, but these foods are a particular risk for harboring the bug as processed or pre-cooked foods can become contaminated during the packaging process.

Who is most vulnerable to Listeria? Pregnant women, young children, the elderly and adults with weak immune systems (for example, people with HIV or AIDS, transplant patients, those who have cancer or those who regularly take steroids or other medications that weaken the immune system) are most vulnerable to listeria infection. These groups may become ill after eating food contaminated with only a small number of bacteria, which a healthy person would be able to eat without being harmed. People who are at risk are particularly advised to avoid eating any soft cheeses or pâté (including vegetarian pâté).

What are the symptoms? Listeria infection has a variety of symptoms. Healthy adults may experience mild flu-like symptoms, such as fever, muscle aches and mild gastrointestinal symptoms, including nausea or diarrhea. Headache, confusion and altered consciousness may develop if the infection progresses and becomes severe.

How do I avoid Listeria infection? Vulnerable groups are more likely to experience severe illness or complications. In particular, pregnant women can experience miscarriage, premature delivery or stillbirth or can pass the infection on to their baby. Serious illness and complications can be prevented by prompt medical treatment and antibiotics. Dr. Andrew Wadge, Chief Scientist at the FSA, has said that 95% of cases need hospital treatment.

There are several simple ways to avoid a listeria infection. The FSA advises the following:

- 1.** Don't eat foods that are past their use-by date, even if they smell fine. Use-by dates indicate how long a food will remain safe (if food is frozen or cooked before the use-by date, it can be kept for longer).
- 2.** Follow the storage instructions on food packaging, such as 'freeze on day of purchase', 'cook from frozen' or 'defrost thoroughly before use and use within 24 hours'.
- 3.** Make sure your fridge is at the right temperature, ideally between 0°C and 5°C.

Cases of food poisoning double in frequency during the summer months, when food exposed to the heat can go off more quickly. It is important to be careful when handling and preparing food:

- A)** Wash your hands and keep work surfaces clean.
- B)** Make sure that reheated pre-prepared foods are steaming hot before you eat them.
- C)** Only eat pasteurized dairy produce.
- D)** Be careful when storing foods from tins or packages, for example don't keep open tins in the fridge.

As a side issue, the 'best-before' date, which also appears on a wide range of foods, is an indication of the quality of food, rather than its safety. Food eaten after a best-before date may not taste as good as it did before, but it will not do you any harm (with the exception of eggs, which should not be eaten after best-before date).



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](#).

Have a Safe and Healthy Spring Season!



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