



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: Tuesday January 19, 2016 3:30pm – 5:30pm
451 Junction Road
UW West Clinic Room 1287
Enter the clinic... proceed left past the vending area... turn left again and conf. room 1287 is the last one on the left.

Information: Jayne Schwartz 608- 244-2120
schwartzdon@sbcglobal.net

Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue
Madison, WI 53714-1815

More Information:

International Myeloma Foundation (IMF)	Multiple Myeloma Research Foundation (MMRF)
Phone: 800 - 452 - 2873	203 - 972 - 1250
Email: TheIMF@myeloma.org	info@themmrf.org
Website: www.myeloma.org	www.multiplemyeloma.org

Upcoming speakers

- **February** meeting will be split into two separate meetings. Caregiver’s meeting facilitated by Jayne and the MM patient’s meeting facilitated by Don.
- **March** meeting- Sue Enright from the IMF will speak to the group. Weather permitting.
- **Confirmed April** meeting speaker- Jill Helgeson from SHIP-(State Health Insurance Program).
- **June meeting-** Dr Aric Hall, UW Hematology faculty member will do a Q&A starting at 4:30pm

January meeting speaker- Tim McNeill, author of *The Ultimate Marathon: My Journey With Multiple Myeloma Cancer*. Diagnosed in June 2002, Tim has an amazing story to tell.

Thank you to our group members Larry and Mary Lou Hudack and Ruth McNeil. You generous contributions help us continue to produce and send the newsletters. I continue to hear from our postal group members that the newsletters are very valuable to them.

Thank you to Santa and Mrs. Claus for making a stop at the December meeting. After passing clinic security (!), they handed out the new Takeda cook book entitled, “Cooking through Cancer Treatment and Recovery”. My thanks to Takeda for their continued support of groups everywhere.

Recap of the December meeting with Peggy Wellman from Takeda “Understanding Your Myeloma Lab Tests”.

Peggy helped us understand the CBC (Complete Blood Count) tests, Chemistry Profiles, Serum Protein Electrophoresis (SPEP), Serum Quantitative Immunoglobulins (Igs), Serum Immunofixation (IFE), Serum Free Light Chain Assay and 24-Hour Urine tests. The handout made these topics easy to understand. With so many tests ordered to follow a Myeloma diagnosis, any simple to read information is appreciated. Peggy made this easy to understand. Mission accomplished!

You can still hear Dr Brian Durie's, **Best of ASH presentation**. Find it on the IMF website.

Here is the link for the **September 2015 LLS Conference** presentations.

<http://www.lls.org/wisconsin/article/patient-education-wisconsin?src1=21811&src2=>

Maddie Hunter from the Philadelphia group put together some interesting links.

1. <http://ash2015blogs.myeloma.org/> - A team of IMF support group leaders was formed to provide the patient perspective of attending ASH. Check out this link to read their varied thoughts. Philadelphia group member, Cindy Chmielewski was part of this team.

2. <http://myeloma.org//ArticlePage.action?tabId=22&menuId=164&articleId=4710&aTab=-1&gParentType=menuitem&gParentId=164&parentIndexPageId=7&parentCategoryId=283> - This IMF sponsored link takes you to a series of debates on current topics about MM. Notable physicians present their contrasting views on the following questions. Interesting!

a. [Debate 1: Will New Diagnostic Criteria and Early Treatment Improve Survival or Result in More Aggressive Disease at Relapse?](#)

[Debate 2: Should Risk-Adapted Therapy Be Used for Patients With Newly Diagnosed MM?](#)

[Debate 3: Should MRD Be Used to Guide Treatment Decisions Regarding Maintenance Therapy?](#)

[Debate 4: Are Emerging Systemic Therapies Best in Patients With Newly Diagnosed or Relapsed MM?](#)

3. <http://www.themmr.org/ash/> - The MMRF has provided some resources on the key takeaways from ASH.

Our newest drugs just approved by the FDA for use.

Ninlaro®, also known as **ixazomib**, is a type of cancer drug called a proteasome inhibitor. Ninlaro is in the same class of drugs as Velcade® (bortezomib, Takeda Oncology) and is made by the same company. It is considered to be a second-generation proteasome inhibitor because it has improved characteristics and activity over Velcade. Ninlaro is an oral medication. **How does Ninlaro work?** Ninlaro is a proteasome inhibitor. Proteasomes are enzymes found in cells that help the cell break down old or unwanted proteins. These proteins are split into amino acids which can then be recycled to make new proteins. Cancer cells depend on the proteasome to provide this protein metabolism (turnover) function to regulate their growth and survival. Ninlaro disrupts a cancer cells ability to survive by blocking the proteasome and disrupting protein metabolism. Myeloma cells may be uniquely sensitive to proteasome inhibitors because they make large amounts of protein (called M-protein) and need this recycling function to survive.

Empliciti™, also known as **elotuzumab**, is a monoclonal antibody. Empliciti is made by Bristol-Myers Squibb and AbbVie. **How does Empliciti work?** Empliciti binds to the SLAMF7 protein, also known as CS1, expressed on myeloma cells. Empliciti directly activates immune cells known as Natural Killer (NK) cells and, by binding to SLAMF7, facilitates NK-mediated killing of myeloma cells. Empliciti™ (elotuzumab, Bristol-Myers Squibb/AbbVie) is given as an intravenous (IV) infusion. It is given along with Revlimid® (lenalidomide, Celgene) and dexamethasone once a week for the first two cycles and every 2 weeks thereafter.

Darzalex™, also known as **daratumumab**, is the first monoclonal antibody approved for use in multiple myeloma. Darzalex is made by Janssen Biotech and Genmab. **How does Darzalex work?** Darzalex binds to CD38, a marker found on the surface of myeloma cells. It is thought to inhibit myeloma cell growth in several ways, including by directly affecting myeloma cells by enabling immune cells to kill myeloma cells. Darzalex™ (daratumumab, Janssen/Genmab) is given as an intravenous (IV) infusion.

More information on all of these new treatments can be found on the IMF website.

Save the date....

April 30-May 1, 2016 “Celebrating a Second Chance at Life”, a symposium for bone marrow, stem cell and cord blood transplant survivors. Register now at www.bmtinfonet.org/Chicago2016 or phone 888-597-7674

IMF Info Line – If you or someone you care for has myeloma, you have questions. Probably, lots of them. You can search the Internet all you want, but other than asking your doctor, there is no better way to get your questions answered than to call the IMF Info Line. Debbie, Missy, Judy and Paul know their stuff and they want to share what they know with you. Just ask anyone who has called the IMF Info Line. Patients or caregivers are welcome to contact the Info Line staffed by trained specialists at 800-452-CURE (800-452-2873). The Info Line is staffed between 9am and 4pm Pacific Time, 11am to 6pm Central time or infoline@myeloma.org.

The **Trillium Fund** was established by our founding support group members to facilitate Multiple Myeloma research here in Madison at the Wisconsin Institute of Medical Research. If you or your family wish to donate or send a memorial to this program, checks can be made payable to the “UW Foundation – Trillium Fund”.

Katie Williquette

UW Carbone Cancer Center

600 Highland Avenue, K4/658

Madison, WI 53792-6164

(608) 263-0160

kwilliquette@uwcarbone.wisc.edu