



“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 October 16, 2018 3:30pm – 5:30pm
451 Junction Road
Madison, WI
UW West Clinic Room 1287

Enter the clinic... proceed left past the vending area... turn left again and conference room 1287 is the last one on the left.

Group Information:

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Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

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

Information Sources :

International Myeloma Foundation (IMF)
Phone: 800 - 452 - 2873
Email: TheIMF@myeloma.org
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Upcoming Meeting Speakers... **Mark your calendars now!**

Dr Sara Christensen Holz, Associate Professor Dept of Orthopedics and Rehabilitation had to reschedule. She is currently looking at January or February 2019 as possible dates to come. She will talk about balance issues and neuropathy.

Carly Borchert, Clinical Nurse Consultant-Milwaukee District, Celegene Corporation will be our December speaker. Carly will present “The Myeloma Central Tour” and speak briefly about the Myeloma Crowd.

Dr Natalie Callander will be the featured speaker at our October meeting. She will be here at 4:30pm. Mark your calendars now and come early to get a seat! Some group members will be wearing their “transplant t-shirts”. If you have one, think about wearing it. It would be fun to see them all.

A big Thank You to Connie Deer and Mary Lou Hudack for their generous contributions to the group. It is very much appreciated and will go towards the newsletter distribution.

Medicare and open enrollment time...Just wanted to remind everyone about **SHIP- State Health Insurance Assistance Program**. Every state has one and if you have questions about Medicare, etc, they are available to help you. Call now and talk to one of the representatives. The time to do this is now!

IMF Advocacy update!

Legislation to ban pharmacy gag clauses is moving forward!

Pharmacy gag clauses prevent pharmacists from informing patients whether or not their drugs would be cheaper when purchased without using their insurance. The House voted on September 25, 2018 to advance Senate passed legislation banning these practices. Cancer patients face some of the highest out-of-pocket costs and deserve to know when there is a cheaper way to obtain their prescriptions. The House and Senate recently passed two different pieces of legislation to ban gag clauses. S. 2553, the Know the Lowest Price Act bans gag clauses in Medicare and it recently passed through both the House and Senate. Additionally, both chambers also held a vote on S. 2554, the Patient Right to Know Act, which addresses the issue for commercial plans. The bills will now be sent to the President's desk to be signed. The IMF would like thank everyone who has contacted their Members of Congress about this issue and will continue to keep you updated.

DMRP-A Big Win for Myeloma Researchers!

The IMF advocacy team has been working hard to ensure myeloma researchers can continue to apply for research funding through the Department of Defense's Peer Reviewed Cancer Research Program in 2019. Since 2015, myeloma was not a part of the program, but the IMF successfully lobbied legislators for inclusion in 2018. Efforts have been successful once again for 2019! The blood cancer topic area was included in a recent Appropriations bill that was signed into law by President Trump. Myeloma research will continue under this program.

In addition to preserving a spot in the program, the Peer Reviewed Cancer Research Program will receive an additional \$10 million in funding in 2019 and the bill also increases funding for the National Institutes of Health (NIH) by \$2 billion. This is a big win for myeloma research!

The 2nd Annual Multiple Myeloma Patient And Caregiver Symposium was a huge success. The presentations are online at <https://www.mcw.edu/Cancer-Center/MMSymposium.htm>. The subjects are below. This is an amazing opportunity to review what you heard or visit the information for the first time. Kudos to Lori Jemison RN, OCN, BMTCN Clinical Coordinator for a great conference.

[Amyloidosis- What does it have to do with Myeloma?](#)

[Autologous Transplantation in Multiple Myeloma](#)

[Cancer Phytochemicals](#)

[A Cancer Fighting Diet](#)

[Cellular Immunotherapy for Myeloma](#)

[Allogeneic Hematopoietic Cell Transplantation for Multiple Myeloma](#)

[Foods that Fight Cancer](#)

[MGUS and Smoldering Myeloma: Risk stratification and Therapeutic Options](#)

[Multiple Myeloma and Understanding your Labs](#)

[Multiple Myeloma Therapies: What Lies in the Future?](#)

[Sparkcures Presentation](#)

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. 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”. Sean Lynch Director of Development UW Carbone Cancer Center University of Wisconsin Foundation 1848 University Ave Madison, WI 53726 (608) 422-1714 cell sean.lynch@supportuw.org

www.mycarbone.org has been established as an easier way to contribute. Check it out!