



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

Meeting: **Meetings will resume when we are allowed to gather at the address below.**

451 Junction Road  
Madison, WI  
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:

Jayne Schwartz 608- 244-2120  
[schwartzdon@sbcglobal.net](mailto:schwartzdon@sbcglobal.net)

Madison Multiple Myeloma Support Group website  
[madisonmultiplemyeloma.org](http://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](mailto:TheIMF@myeloma.org)  
Website: [www.myeloma.org](http://www.myeloma.org)

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

### **October 2020 Myeloma Newsletter**

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

**Dr Natalie Callander, UW Carbone Cancer Center** This will be a virtual presentation for the November 17th meeting. She will join us at 4:30pm.

**Please note that the previously scheduled date for Dr Natalie Callander has been changed. Patients come first and patients were scheduled for that October date. She has rescheduled for the November 17<sup>th</sup> meeting.**

#### **Our condolences to the family of Kathleen (Katie) Ann Loehr-Lishka**

Katie passed away on August 24, 2020. She joined our group October 2018. Although, she did not attend all of our meetings in person, she did enjoy the newsletters. Often she would email to share a thought or ask a question. We had some very good conversations. I always appreciated her feedback. She will be missed.

**Our 1<sup>st</sup> Virtual meeting went pretty well.** Your invitation for the 2<sup>nd</sup> one is at the bottom of this newsletter. Our last meeting, some people didn't realize that the invitation included in the September newsletter was their link to join.

The invitation will allow you to join the meeting from your computer, tablet or smartphone. It is

important to not to telephone in if you have already clicked on the link to sign in on your computer, tablet or smartphone. The two audios will compete with each other causing a continuous loop for sound. It resembles screeching like you dialed a Fax phone number instead of the right one. An awful noise! If your desktop computer does not have the audio activated, you will have to telephone in.

If you don't have a webcam on your computer, you probably don't have a mic either and should telephone in. You will not be able to see me leading this meeting as my desktop computer does not have a webcam. As a telephone caller, I will be a black box- no picture.

No computer, no problem. Use toll free 1-877-309-2073 when dialing in. There are limitations to the number of participants when you use the toll free number given in the invitation.

It is very important that we use conversational courtesies. Let's make sure that we don't talk over other people's conversations. It is going to be hard but I know we can do it.

If this does not go well, I will try to mute the mics of one of your multiple sound choices. If I cannot get sound clarity, I will need to drop the meeting and try again later.

During Dr Callander's presentation, all of us will be muted as she presents. If you click on "Hide Everyone", your screen will become larger and the presentation will be in full screen. There will be time for questions allowed later.

**During the IMF Patient and Family Webinar on October 3<sup>rd</sup>**, there was a reference about a collection of thoughts and tips from Caregivers. It is titled "What I Wish I Had Known When My Loved One Was First Diagnosed". I emailed the IMF for that document and it is attached for your reading. We often don't find much for our caregivers but this is a good one. Document was too long to print and mail for those folks without the email options. Sorry...

**From our group member, Gwen-**

<https://www.businessinsider.com/katie-porter-executive-mark-alles-price-hikes-cancer-drug-revlimid-2020-9?amp>

This link provides you a glimpse of how important it is to continue to contact your representatives to work on drug pricing issues. Kudos to U.S. Representative, Katie Porter (D-CA) for her strong presentation and dedication to this issue.

**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](mailto: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" and sent to UW Carbone Cancer Center, University of Wisconsin Foundation, 1848 University Ave, Madison, WI 53726. Donations may also be made online at [www.supportuw.org/give](http://www.supportuw.org/give) (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Daniel Rosen at (608) 264-5437 or email [curecancer@supportuw.org](mailto:curecancer@supportuw.org).

**Invitation for the virtual November 17<sup>th</sup> Support Group meeting.**

Madison Multiple Myeloma Support Group  
Tue, Nov 17, 2020 3:30 PM - 5:30 PM (CST)

**Please join my meeting from your computer, tablet or smartphone.**

<https://global.gotomeeting.com/join/555030645>

**You can also dial in using your phone.**

United States (Toll Free): [1 866 899 4679](tel:18668994679)

United States: [+1 \(571\) 317-3116](tel:+15713173116)

**Access Code:** 555-030-645

New to GoToMeeting? Get the app now and be ready when your first meeting starts:

<https://global.gotomeeting.com/install/555030645>