



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

Meeting: **In person 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

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

Myeloma Crowd /Health Tree Foundation
P.O. Box 1286
Draper, UT 84020
www.myelomacrowd.org

September 2022 Myeloma Newsletter

Upcoming Meeting Speakers

Dr Natalie Callander, UW Carbone Cancer Center will be our featured speaker for the October 18, 2022 meeting. She will start at 4:30pm.

Rozalynn Hite from Healthtree Myeloma Crowd will be our featured speaker November 15, 2022. She will be presenting information about Healthtree and the Chapters. She will join us at 4:30pm CST. She is Director of Coaching but she does a little bit of everything there.

Wisconsin's State Health Insurance Assistance Program (SHIP) provides outreach and assistance to Wisconsin Medicare Beneficiaries. It is a federally funded program. Sharon and Jill will join us at 3:30pm and present their program, “Welcome to our Medigap Staff” at our September 20th meeting. They will talk about who they are and what they do. They will also present information about the different Medicare options, when to do a review and how to best pick a plan. Mark your calendar now so you don't miss this presentation.

Got any Hot Rocks?

Our group member, Lori would like to introduce a new idea to get conversations started during our group share time. The concept of a “Hot Rock” would prioritize something big that has happened that they want to discuss with the group. This does prioritize topics and still allows for everyone to get time to share their updates during the meeting. Lori would like to share her experience with how this can benefit our group.

Something else that I would like to suggest..... That we save our discussions about Covid, Covid treatments and vaccines for the end of our meetings. I know this topic is very important and offering new information benefits all folks, but we may be spending too much time on it if it is introduced during the beginning of our meetings. And, not allowing enough time for group members to really get some help with their current Myeloma experiences.

Update! This is new information about the Trillium Research Fund.

We have a new contact, Janie Winston.

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 (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Janie Winston 608-512-6068 or email at Janie.Winston@supportuw.org.

Talquetamab – Breaking news for another treatment option.

HealthTree for Multiple Myeloma recently posted [summary results of several studies that included Talquetamab](#) as part of the clinical treatment program. Talquetamab is an investigational, off-the-shelf, T-cell redirecting bispecific antibody.

It targets the novel biomarker, GPRC5D on multiple myeloma cells and CD3 on T-cells. On June 29, 2022, Johnson & Johnson/Janssen [announced](#) that the US Food and Drug Administration (FDA) granted Talquetamab “Breakthrough therapy designation”.

[Breakthrough Therapy designation](#) is a process designed to expedite the development and review of drugs that are intended to treat a serious condition and preliminary clinical evidence indicates that the drug may demonstrate substantial improvement over available therapy.

The expedited approval process benefits all myeloma patients, and all indications are that this new product will arrive into clinical practice in a few months.

Our virtual meetings are on the Zoom platform.

Our meeting for September 20, 2022 will be from 3:30pm to 5:30pm featuring WI SHIP representatives, Sharon and Jill. They will present at 3:30pm .

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQU2FOZ1hMUkFaRmJBc0Qzdz09>

Meeting ID: 844 5766 7535

Passcode: 678275

One tap mobile

+13017158592,,84457667535#,,,,*678275# US (Washington DC)

+13126266799,,84457667535#,,,,*678275# US (Chicago)

Dial by your location

+1 301 715 8592 US (Washington DC)

+1 312 626 6799 US (Chicago)

+1 646 558 8656 US (New York)

+1 253 215 8782 US (Tacoma)

+1 346 248 7799 US (Houston)

+1 669 900 9128 US (San Jose)

Meeting ID: 844 5766 7535

Passcode: 678275

Find your local number: <https://myeloma-org.zoom.us/u/kyMbCRs05>

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 specialist 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.

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