



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

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

HealthTree Foundation
P.O. Box 1286
Draper, UT 84020
www.healthtree.org.

Leukemia & Lymphoma Society
(includes Multiple Myeloma)
Contact information 1-800-955-4572
Email www.LLS.org/ContactUs
Live chat www.LLS.org/patient-support

September 2024 Myeloma Newsletter

Upcoming Meeting Speakers

No meeting for October 15, 2024.

Nancy Bruno, IMF Director of Support Groups will be our featured speaker for the November 2024 meeting. More info to follow.

Dr Natalie Callander, UW Carbone Center tentatively will be our December 2024 meeting speaker. More info to follow.

Shannon Ramirez, BSN, RN, OCN-Oncology Clinical Educator- S. Wisconsin, Illinois, NW Indiana, Quad Cities Hematology from **J&J Innovative Medicine** will be our featured speaker January or February 2025. Date and topic to be determined later.

Very important message for everyone!

Your Zoom invitation has a new sign on. The IMF has given each group their own email address. We were sharing our address with the San Gabriel, CA group. If you have the previous Zoom sign-in saved somewhere for easy access, please delete it now. Use this new one. I will be repeating this message for several months so that group members

don't miss this news. It is very important to not sign in using the old information. New Zoom information is at the end of this newsletter.

Steve Shapiro, Medigap Insurance and Wisconsin SHIP counselor will be our featured speaker for the September 17th group meeting. SHIP is the State Health Insurance Assistance Program.

Steve will be presenting "Medicare and Other Insurance-Fitting the Pieces Together". **He will start his presentation at 3:30pm CST.**

A big thank you to David and Mary Barton for their generous contribution to our support group. It will be used to cover expenses related to our website, postage and mailing. It is very much appreciated.

Another thank you for all who attended the summer picnic and contributed to the Trillium Research Fund in memory of Donald Schwartz. Georgia reports that \$800 was collected and sent to the UW Trillium Research group. Thank you all.

Light the Night, LLS event is October 10th at the Henry Vilas Zoo from 5:00pm to 8:30pm. Our group member Katie will be sending more information about this event. Registration is open now at 1-833-448-3358 or www.lightthenight.org. Make sure you sign up under the Katie Dowling-Marcus team. There is no cost to sign up.

Below is just one of many comments that I got back from sending **Dr Matthew Drake's presentation on Bone Health**. I have included the link again for those that might have also set it aside. About 11 minutes into the presentation, there was a lost connection to the broadcast but that only lasted 24 seconds. This presentation expertly covers the topic of bone health for MGUS, Smoldering and active myeloma. What was very interesting was Dr Drake's comments for those with MGUS and Smoldering. He explains the limitations and options for improved skeleton structure and pain.

Comments:

I had set this lecture on bone health aside when it first came to me. Today I watched it and will agree with many others who tell you it is FABULOUS. It should be "must viewing" for every myeloma patient.

Comment from the moderator - It was a great session with so much information. Even those who were able to attend are interested in reviewing the session again and would like to have the link to do so.

Here is the link that the moderator sent again.

Copy the passcode before you click on the link.

https://myeloma-org.zoom.us/rec/share/WeoBi8uB76HYCF9yc8Bc6imYcDZmT_ZGW_jGdaV6t7Ppii2b1Sad_VwOj_6qo2Xf.GTgGMfVhLBUsOMA

Passcode:DN*5xX7G

REM App for Revlimid users

From our group member, David. He found that there is an app for the Revlimid REM survey that you can load on your phone. I called Bristol Myers Squibb and there is an app for Android users through Google Play. This will save time and is easy to use. See David's comments below.

“Every time a patient orders Revlimid, he/she has to take a survey from the manufacturer with a series of questions reminding them not to share, give blood, etc. Often the patient has to wait on hold for several minutes if they call in.

Bristol Myers Squibb developed this app so the patient can complete the survey in about 45 seconds. **The app even reminds you the earliest date you can take the survey each month.**

This is the apple app. I'm sure there is an android app.”

<https://apps.apple.com/app/id1482319320>

Our virtual meetings are on the Zoom platform.

Our meeting for September 17th, 2024 will be from 3:30pm to 5:30pm. Steve Shapiro, Medigap Insurance and Wisconsin SHIP counselor will be presenting "Medicare and Other Insurance-Fitting the Pieces Together". **He will start his presentation at 3:30pm CST.**

Madison MM Support Group is inviting you to a scheduled Zoom meeting.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/81745782301?pwd=L2u5V0zAxLtuHQtKh2WZZaO3lsvs8N.1>

Meeting ID: 817 4578 2301

Passcode: 636273

One tap mobile

+16469313860,,81745782301#,,, *636273# US

+13017158592,,81745782301#,,, *636273# US (Washington DC)

Dial by your location

• +1 646 931 3860 US

• +1 301 715 8592 US (Washington DC)

• +1 305 224 1968 US

• +1 309 205 3325 US

- +1 312 626 6799 US (Chicago)
- +1 646 558 8656 US (New York)
- +1 386 347 5053 US
- +1 507 473 4847 US
- +1 564 217 2000 US
- +1 669 444 9171 US
- +1 669 900 9128 US (San Jose)
- +1 689 278 1000 US
- +1 719 359 4580 US
- +1 253 205 0468 US
- +1 253 215 8782 US (Tacoma)
- +1 346 248 7799 US (Houston)
- +1 360 209 5623 US

Meeting ID: 817 4578 2301

Passcode: 636273

Find your local number: <https://myeloma-org.zoom.us/j/kfhNZQhIT>

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.

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.