



“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:

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Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

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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. (new URL)

February 2024 Myeloma Newsletter

Upcoming Meeting Speakers

One of the **MMRF nurse navigators** will present at the March 2024 meeting. More info to follow.

Working on getting **Dr Aric Hall, UW Carbone Cancer Center** for the April 16, 2024 meeting.

Working on getting **Dr Zhubin Gahvari, UW Carbone Cancer Center** for the May 21, 2024 meeting. Hoping to get his presentation on Relapsed Myeloma that he shared with us at the recent Multiple Myeloma Research and Patient Care event. The Trillium Research update held October 30th.

Shannon Blake and Christina Nielsen from the Leukemia, Lymphoma Society (LLS) will be our featured speakers for the February 20, 2024 meeting. Christina's topics will be LLS patient and community support materials, educational programs and financial resources. Shannon's topics will include LLS research initiatives and the top funded priorities. Our featured speakers will start presenting at 4:00pm CST.

News to share-

At the August 2023 meeting, we talked about a gap in patient care that we identified as needing a solution but we did not quite know how to move forward with this issue.

I offered to write to the Carbone Cancer Center Patient Relations department, Kim Blue to share our concerns and offer suggestions. Attached is the letter that I sent. (The care that group members get from their provider is exceptional make no mistake about that. How that happens could stop the gap.)

My email to Kim Blue on August 30, 2023 below,

Kim,

The attached letter explains our concerns and offers suggestions. I have cc'd Dr Peter Newcomer and the doctors that many group members see for their treatment.

Our intention is not to criticize or complain about current treatment. Our UW doctors are some of the very best and we know it. We recognize that some MM patients are less than comfortable taking up too much time with their doctors. They are there for treatment and generally spend some significant time in clinic. As not to burden or take up valuable time, some of this subject matter becomes something that they just make the best of.

Just a thought, the navigator might spend some time with the MM patient in the treatment room or infusion center. After all, the time is available. Sounds like a good use of time to me.

Thank you for your time and consideration. I look forward to hearing from you.

Jayne Schwartz

Madison Multiple Myeloma support group facilitator

I have included my initial letter and also the response that I got on January 19, 2024 from Kim Blue. I see this a very positive and am encouraged for the changes. Since that time, I have learned that there are some health facilities that do have Navigators already in place. And the results are very supportive of the individual's care.

If you have any experience with a "Navigator" where you receive your treatment, I would be very interested in hearing your thoughts and opinions as to the effectiveness of this role with your care.

As always, share your concerns with your doctors and nurses. They need to know how you are doing and really do want to make changes to your benefit. It takes time but this time is valuable for good outcomes and better days.

Our group member, David Barton is a HealthTree Foundation coach. He is amazing and always available to help answer questions. He sent this link for folks that want to know more about Navigators. Thank you David.

*. This link does a nice job of describing the benefits of Nurse Navigators for MMers.
<https://aononline.org/navigation-tools/4878:navigating-multiple-myeloma-the-critical-importance-of-the-first-90-days>

Especially toward end of article. The added cost can lead to payback (eg if some of the 30% of patients who don't take their oral meds start taking them.)

Our virtual meetings are on the Zoom platform.

Our meeting for February 20, 2024 will be from 3:30pm to 5:30pm. Our featured speakers will start presenting at 4:00pm CST.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0IJTDNQ2FOZ1hMUKFaRmJBc0Qzd09>

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.

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.