



“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

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. (new URL)

March 2024 Myeloma Newsletter

Upcoming Meeting Speakers

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.

Tom Vodicka will be our featured speaker for either the June 18th or July 16th meeting. Date to be determined later. Tom was our featured speaker at the December 2023 meeting. Tom will continue with his topic of “Life and Wills”.

Brittany Hartmann, MMRF Patient Navigator will present at the March 19, 2024 meeting. Her topic will be Patient Navigators. Mark your calendar now not to miss this meeting. Presentation start time is still to be determined.

Our condolences to the family of Ivan (Red) Henning.

Red joined our group December 2004. He had a stem cell transplant April 2000 and was just shy of 24 years without medication or evidence of disease. He passed March 8, 2024 from an injury. Red attended meetings when he could and was always ready to share his experience. He was an inspiration to many and just a kind and genuine person. He will be missed.

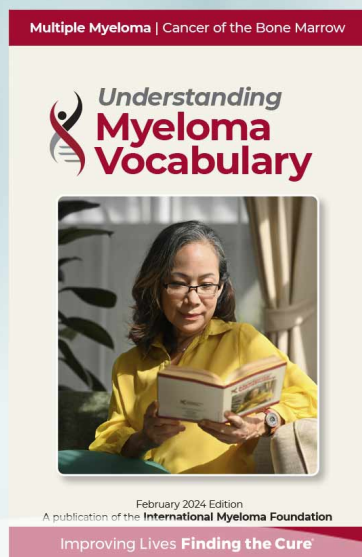
Follow up information from the Leukemia, Lymphoma Society (LLS).

Here is the link to **Advocacy Page** where you can sign up to be an advocate:

<https://www.lls.org/policy-advocacy>

- Save the Date: **Madison Light The Night October 10th, 2024** Henry Vilas Zoo
<https://ltn.stg.lls.org/upln>
- Here is the phone number for the **Information Resource Center: (800) 955-4572.**
- Christina did reach out to the Financial Assistance team about the change from 12K to 5K in funding for CoPay and they gave her a similar response to what someone mentioned at the last meeting. They said they have had such a surge of families coming to LLS for Support that the funds were being depleted too fast and they changed the limit to accommodate more families.

Here is a new booklet that you can order or download from the IMF Educational site. Easy to take with you to appointments.



Download *Understanding Myeloma Vocabulary*

Myeloma is a complicated disease, but the language that describes it doesn't have to be hard to understand. To play an active role in your own medical care, it is helpful to learn the myeloma-related terms that may be used in your discussions with your doctor, who is best able to answer questions about your specific healthcare management plan.

Our virtual meetings are on the Zoom platform.

Our meeting for March 19, 2024 will be from 3:30pm to 5:30pm.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQ2FOZ1hMUkFaRmJBc0Qzd09>

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/j/84457667535?pwd=V0lJTdNQ2FOZ1hMUkFaRmJBc0Qzd09>

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 info@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.