



“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.

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

April 2024 Myeloma Newsletter

Upcoming Meeting Speakers

Dr Zhubin Gahvari, UW Carbone Cancer Center will be our featured speaker for the May 21, 2024 meeting. He will be repeating 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 on October 30th. He will join us at 4:30pm CST. Mark your calendar now.

Tom Vodicka will be our featured speaker for July 16th meeting. Tom was our featured speaker at the December 2023 meeting. Tom will continue with his topic of “Life and Wills”.

Dr Aric Hall, UW Carbone Cancer Center will be our featured speaker for the April 16, 2024 meeting. He will likely be joining us at 4:30pm CST. This meeting is a group favorite as it is all Q & A. No question is off limits.

Our condolences to the family of Nona Suhr

Nona Suhr age 94 passed away April 3, 2024. Nona joined our group December 2005. She had been diagnosed smoldering Myeloma. She was one of our longest smoldering group members. To my knowledge, her myeloma did not become active. She attended many meetings early on and was always cheerful and positive. The encouragement that she gave everyone made her a favorite among our group members. Her humor was her strength. “Delightful” describes her. She will be missed.

Please note that there will be no support group meeting on June 18th. We will be meeting at Marshal Park for an afternoon picnic. I hope that all that can attend will do so. Keep tuned as more information will be coming. See attached info.

Over the last several months we have heard from many of our organizations that support Myeloma patients, family, caregivers and support groups. They are continuing to provide resources that are ever changing. In October 2023, Nancy Bruno from the IMF. January 2024 our speaker was Todd Foster from HealthTree Foundation. February 2024 speakers were Shannon Blake and Christina Nielsen from the LLS. And then in March 2024, Brittany Hartmann from the MMRF.

We were amazed by all the resources and support that has been developed over the years. One common theme is that it is comprehensive and aims to support the patient, family, caregivers and support groups. Easy to use websites and plenty of subjects to gain more insight into living well. I hope you enjoyed their presentations.

As always you can find their contact information at the beginning of each newsletter. Reach out and preview what is there for you. It is impressive.

From the HealthTree Foundation -What Is Myeloma Coach?

Posted March 2024

[The Myeloma Coach program](#) is a **free program** focused on helping patients find and use the best myeloma resources. They understand that having multiple myeloma is not easy so they have put together a team of myeloma patient and caregiver volunteers who can help you. Whether that means helping you find a myeloma specialist, learning about financial resources, or using online tools that can help you live longer and better with multiple myeloma.

Who Are The Coaches?

Myeloma Coaches come from a variety of backgrounds. Coaches may be a myeloma patient themselves, a caregiver, adult child or an extended family member of a myeloma patient. Each Coach has played a role in a myeloma journey whether their own or with someone they care about. Myeloma Coach Director, Rozalynn Hite recently wrote an article highlighting "[Top 10 Reasons To Work with a Myeloma Coach](#)" and how important a Coach can be for a patient.

While their roles may be different, each have traveled the road of myeloma, with all of its twists and turns. They have experienced the shock and disbelief upon diagnosis. They have felt the flood of emotions and feelings of being completely overwhelmed with an instant outpouring of medical information, genetics, labs, and treatment options. They have searched for reliable resources, a myeloma specialist, ways to combat treatment side effects, or for financial resources and support. They may have been involved in making preparations for stem cell transplant.

How To Find A Coach

Remember, the Myeloma Coach program **is completely free**. All Coaches willingly volunteer their time to help patients like you! Many are myeloma patients, others are caregivers, scattered across the nation ready to help.

Our group member, David Barton is a HealthTree Foundation coach. He is amazing and always available to help answers questions.

Our virtual meetings are on the Zoom platform.

Our meeting for April 16, 2024 will be from 3:30pm to 5:30pm. Our featured speaker will be Dr Aric Hall from the Carbone Cancer Center at the UW. He will join us at 4:30pmCST.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQQU2FOZ1hMUKFaRmJBc0Qzdz09>

Meeting ID: 844 5766 7535

Passcode: 678275

One tap mobile

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+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>

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.