



“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

July 2024 Myeloma Newsletter

Upcoming Meeting Speakers

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

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

David Barton, our very own support group member and Myeloma Coach will be our featured speaker for the July 16, 2024 meeting. David's presentation will be “The Patient's Perspectives from Newly Diagnosed and Beyond”

Thank you to our picnic committee!

Our committee- Gloria and Mike Green, Tony and Darlene Nowak and Georgia Kinder did an amazing job with the planning and organizing a perfect afternoon for us all. Food was great. Meeting new people (in person!) and catching up with the many support group members that we often don't see virtually was the highlight of the day. Thank you for a very thoughtful memorial to Don and recognizing my work as your fearless leader (quoting Georgia!). The park was great and not too hot. A very good choice for sure. Thank you to all that attended. I hope you had a great time.

Thank you to Joanie and Karen for their generous contribution to the support group.

As always, it will go a long way to help with the cost of postage, printing and copying of the newsletter each month.

Our condolences to the McNeil family.

Ruth McNeil was a long time supporter of our Myeloma group. Ruth passed away June 29, 2024. The McNeil family joined our group July 2002. Son, Tim has Myeloma. Tim wrote a book and one of his sisters was a featured speaker at a meeting a long time ago. She spoke about her family's caregiving role and of their role in making sure that Tim got the best treatment possible. Tim later wrote a book and the description is below. At one time, I had a copy and lent it out. It didn't come back.

The Ultimate Marathon: My Journey With Multiple Myeloma Cancer

by **Tim McNeill**

The story you are about to read is being told by me, the patient, who lived this experience. It also includes information from the caregivers who gave of their time to help out in any way that they could. This book will show where my family spent the better part of four years of their lives, sleeping in hospital waiting rooms, waiting on me, worrying, and researching all the possible treatments that could help in my case. When you have a Mum and five sisters who are persistent, relentless and don't accept the word "No?", it makes for interesting stories. When I was first diagnosed with multiple myeloma, my family started keeping a daily journal of everything that was going on in my presence and behind the scenes. My family filled several journals, which included medical information as well as their thoughts about what they witnessed during this journey. This book contains information from those journals, and how I made it through with their help and a lot of other supportive people. In the end it wasn't just a marathon, it was the ultra marathon; not only for myself and my family but my oncology doctor as well. He has never had a patient like me and probably never will. This is my story.

What is MRD testing? Posted May 29, 2024 HealthTree

According to experts, minimal residual disease (MRD) is the name given to small numbers of cancer cells from the bone marrow that remain in the person during treatment or after treatment when the patient is in remission. It is the major cause of relapse in blood cancers, including multiple myeloma and leukemia. Ultra-sensitive molecular biology tests can measure minute levels of cancer cells in tissue samples, sometimes as low as one cancer cell in a million normal cells.

Why is MRD Testing Used in Myeloma?

MRD testing has several important roles: determining whether the treatment has eradicated the myeloma or traces remain, comparing the efficacy of different treatments, monitoring patient remission status as well as detecting recurrence of the myeloma, and choosing the treatment that will best meet those needs.

To read more, check out the HealthTree website for this article.

Our virtual meetings are on the Zoom platform.

Our meeting for July 16, 2024 will be from 3:30pm to 5:30pm. Our feature speaker will be our group member, David Barton. David's presentation will be, "The Patient's Perspectives from Newly Diagnosed and Beyond"

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQQU2FOZ1hMUkFaRmJBc0Qzdz09>

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.