

"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 <u>Madison Multiple Myeloma Support Group website</u> schwartzdon@sbcglobal.net madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group

3309 Chicago Avenue Madison, WI 53714-1815

Information Sources:

International Myeloma Foundation (IMF) Multiple Myeloma Research Foundation(MMRF)

Phone: 800 - 452 - 2873 Phone: 203 - 972 - 1250 Email: TheIMF@myeloma.org Email: info@themmrf.org

Website: www.myeloma.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

August 2025 Myeloma Newsletter

Upcoming Meeting Speakers

Shannon Ramirez, BSN, RN, OCN Oncology Clinical Educator J & J Innovative Medicine will be our featured speaker for the September 16th meeting. Topic to be determined later.

Brittany Hartmann, Patient Navigator from the MMRF will be our featured speaker for the October 21st meeting. Topic to be determined.

Dr Zhubin Gahvari, Hematology/Medical Oncology from the UW Carbone Cancer Center will be our featured speaker for the December 17, 2025 meeting. This meeting is on a Wednesday to accommodate Dr Zhubin's schedule. Mark your calendars for Wednesday and not Tuesday. He will be sharing some results of the ASH conference as well as a Q &A session for us.

No virtual group meeting on August 19th.

Save the date! We are planning an outdoor Potluck Picnic for August 19th. Lewis Park 5012 Highland Drive in McFarland, WI has been reserved. Your invitation is included with this newsletter. Important to RSVP. Mark your calendars now.

Also attached to this newsletter is David's presentation "Understanding Your Myeloma Labs". At our last meeting, David gave a detailed explanation of what these labs will tell you and how to place value on what they mean. As always, ask your medical team any questions that you might have about your results. David's closing remarks...When in doubt, call your doc. Don't panic!!!

My closing remarks is to remind you all that David is available to you as a HealthTree trained coach.

Just finished reading a book authored by Kathy Giusti, founder and CEO of the Multiple Myeloma Research Foundation (MMRF). The book is titled "Fatal to Fearless - 12 Steps to Beating Cancer in a Broken Medical System". It is a personal story of her journey with Myeloma and how she founded the MMRF to address the broken system she encountered. It is an amazing story.

<u>Part 1 The Wake Up Call</u> explains the importance of understanding the diagnosis. Goes into detail about finding the specialists that you need on your team. Rethinking what matters most to you. Making your action plan.

<u>Part 2 Buying Time</u> Getting the right team, tests and treatments. Getting the right clinical trial if available.

<u>Part 3 Living Ahead</u> Time to reset your life. Time to recognize your caregivers. Never miss a screening whether related to Myeloma or just the regular screenings that are so important. How to protect your family.

Part 4 The Final Reset How to do this.

I found this book to be a wealth of good information. It is a deeply personal story that details the many steps Kathy took with her team of doctors, caregivers and her family. The many steps that I am sure group members can relate to. Kathy has had Myeloma for more than 25 years and has battled a breast cancer diagnosis in the midst of all of this. Your library may have a copy. Walmart and Amazon do have them. Now days... Walmart and Amazon have everything!

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 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

Madison MM Support Group will be attending a picnic so there is no meeting scheduled for August 19, 2025. Virtual meetings to resume on September 16, 2025.