



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: **In person meetings will resume when we are allowed to gather at the address below.**

451 Junction Road
Madison, WI
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

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

Myeloma Crowd /Health Tree Foundation
P.O. Box 1286
Draper, UT 84020
www.myelomacrowd.org

August 2022 Myeloma Newsletter

Upcoming Meeting Speakers

Reached out to WI SHIP to present at our September meeting. Wisconsin’s State Health Insurance Assistance Program (SHIP) provides outreach and assistance to Wisconsin Medicare Beneficiaries. Even if you don't live in Wisconsin, every state as SHIP. It is a federally funded program. More info to follow.

Dr Natalie Callander, UW Carbone Cancer Center will be our featured speaker for the October 18, 2022 meeting. She will start at 4:30pm.

Kimberly A. Gibbs RN, BSN, OCN.,Patient Advocacy Liaison from Takeda Oncology will be our featured speaker for the August 16, 2022 meeting. Topic will be “Infection Risks and the Importance of Vaccinations”.

Our condolences go out to the families of Will Cummings and David Spooner.

David Spooner passed away June 7, 2022. He joined our group September 2019. Always wanting to learn more, he was an active participant in our group. He was a joy to have in our group. He will be missed.

Will Cummings was killed Monday, August 1, 2022 riding his electric bike on the East side of Madison. He was involved in a bike and box truck accident. A friend reached out to me to let me know of his passing. She said he loved riding all around Madison with his new bike and had moved from Verona some time ago to live with a friend. Will joined our group January 2017 and was an active participant. He easily shared his story with the new members of our group and was always kind and thoughtful. He had many friends within the group. We will miss him dearly.

Thank you to group member David for sharing this unique perspective on living with a chronic illness.

How to live with chronic illness | Psyche Guides

For those folks who do not have the internet/web to click on the above link, here are the key points –

1. It's not about going back: it's about moving forward. You aren't going to be able to go back to a pre-illness state. Instead, you need to figure out how to move forward in the context of chronic illness.
2. You write the narrative. No matter how sick you are or how progressive your disease is, you can take some agency over how you write the rest of your life.
3. Shift your vocabulary. Focus on positive rather than negative words, like what you can do instead of what you can't do.
4. Make lifestyle changes. Ask yourself: 'What lifestyle changes would honor my health, my needs, and my shifted vocabulary? What changes will help me have as many good days as possible?'
5. Pace yourself, learn your limits, and set boundaries. Figure out what lifestyle gives you the best chance of staying in 'maintenance mode'. Then honor your limits and speak up for your needs.
6. Seek the right support. Find people who are willing to walk the journey with you, even if they don't completely understand your situation. Research treatments and practitioners to make sure you're getting the best possible care, and remember that you need to look after your mental and emotional health in addition to your physical health.
7. Allow yourself happiness and fun! You deserve – and need – breaks and joy just as much as a healthy person.

An excerpt from Dr Durie's blog of July 14, 2022 What does the future hold?

Hopes and Challenges for 2022-2026 and Beyond: The Future is Bright

Immune Therapies

The introduction of so many new immune therapies—such as CAR T cells and bispecific antibodies, in addition to other novel agents—offers great hope. This optimism covers both improving outcomes and potentially achieving a cure for some patients.

The next five years will definitely see a steady increase in lengths of remissions as well as overall

survival outcomes. Assessing which options and sequences are best will definitely be a challenge, but these are good challenges to have.

The Black Swan Research Initiative®

The IMF, through the Black Swan Research Initiative®, is strongly committed to continuing research to explore options for achieving both prevention and cure.

A new understanding of the early evolution of myeloma by the iStopMM (Iceland Screens Treats or Prevents Multiple Myeloma) project in Iceland can lead to prevention strategies, as well as early interventions to optimize outcomes.

In the search for the cure, the first results of the ASCENT Trial evaluating the use of daratumumab (Dara) plus carfilzomib, lenalidomide, and dexamethasone (KRd) in high-risk smoldering multiple myeloma (HR SMM) will be presented later this year.

Results will guide the next steps toward achieving long and sustained minimal residual disease (MRD) negative remissions and potential cure. High technology approaches have been used and further refinements, such as use of artificial intelligence (AI) and Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR) gene editing plus sophisticated molecular techniques, will enhance what can be accomplished.

For more of the blog, find it on the IMF website. www.myeloma.org

Our virtual meetings are on the Zoom platform.

Our meeting for August 16, 2022 will be from 3:30pm to 5:30pm featuring Kim Gibbs from Takeda .

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQQU2FOZlhmUkFaRmJBc0Qzd09>

Meeting ID: 844 5766 7535

Passcode: 678275

One tap mobile

+13017158592,,84457667535#,,,,*678275# US (Washington DC)

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Dial by your location

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+1 312 626 6799 US (Chicago)

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+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 specialists 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 Daniel Rosen at (608) 264-5437 or email curecancer@supportuw.org.