



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

Meeting: Tuesday January 21, 2020 3:30pm – 5:30pm
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

Upcoming Meeting Speakers... Mark your calendars now!

Dr Aric Hall will be our featured speaker for the March meeting. He will do a Q & A session starting at 4:30pm.

Cameron Ninos from the UW Cancer Pharmacy is our January meeting speaker. He will not be speaking to the “cost” of medications but will do a Q & A for other questions. I have forwarded some questions in advance. This will help him prepare to get the conversation started. He will be here at 4:30pm.

Can Bone lesions progress when all other tests look good?

Recap of Dr Durie's post dated Dec 5, 2019

The answer to this question is yes. Even though the myeloma has responded very well to treatment, it may be that a little bit of myeloma has remained. It could be persisting in the bone or maybe even increasing slightly in one area of the bone. It is important to keep track of the bone disease.

Bone disease can be assessed by X-rays, CT scan and MRI. A whole-body PET-CT can be extremely helpful if appropriate. This has the advantage of showing where the lesions are on the CT, and whether the disease is active on the PET part of the CT, where there is sugar uptake from the injection at the site of any active myeloma lesions.

Myeloma lesions don't really heal up. There continue to be some small holes in the bone, and so, on X-ray you may continue to see those lesions. Those lesions may be shown to heal on MRI, but healing on MRI occurs very slowly. So, even after six or nine months, even if the myeloma is responding to treatment, it may not be so obvious on an MRI.

The bottom line to this question is, even though the myeloma protein in the blood or the urine can be monitored, and should be monitored, and may be responding very nicely with reduced levels, it is still extremely important to check on the X-rays and scans of the bone to see if anything additional is occurring with that part of the myeloma that may not have fully responded to the treatment.

Work with your doctor to get the best comparison scans or X-rays so you can see if the bone lesions are healing, or if possibly, there is a little bit of myeloma left. This is important because depending upon the results, there may be a change in treatment required.

Fatigue..... one the most common complaints. Have you ever had a tough time explaining how you feel to your loved ones? Try this little story.

"The Spoon Theory", by Christine Miserandino was coined in 2003. The essay describes a conversation between Miserandino and a friend. The discussion was initiated by a question from the friend in which she asked about what having lupus feels like. The essay then describes the actions of Miserandino, who took spoons from nearby tables to use as a visual aid. She handed her friend twelve spoons and asked her to describe the events of a typical day, taking a spoon away for each activity. In this way, she demonstrated that her spoons, or units of energy, must be rationed to avoid running out before the end of the day. Miserandino also asserted that it is possible to exceed one's daily limit, but that doing so means borrowing from the future and may result in not having enough spoons the next day. Miserandino suggested that spoon theory can be helpful for explaining the experience of living with any disease or illness.

Your new normal may likely require a nap, or several if you use too many spoons throughout the day. Give yourself that rest. You need it.

Some group members were asking about "Chemo Brain". Here is a link to a segment that the IMF did on this subject. Segment was produced October 2015.

<https://www.myeloma.org/videos/chemo-brain-it-real-what-myeloma-patients-and-caregivers-need-know-ash-2014>

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.

New information!

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.