



“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:

Jayne Schwartz 608- 244-2120

schwartzdon@sbcglobal.net

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

February 2023 Myeloma Newsletter

Upcoming Meeting Speakers

Dr Aric Hall will be out featured speaker for the April 18th meeting. He will do his usual Q & A and start at 4:30pm.

Our new support group representative from Takeda, Rebekah Tobin will be presenting at the May 16th meeting. “Understanding Lab Values” will be her topic for this meeting.

Dr Timothy Schmidt may be joining us at the July or August meeting. More info to follow. Hoping to get him to talk about his clinical trials.

Michelle Lakner, Nurse Practitioner will be our featured speaker at the February 21, 2023 meeting. I have asked her to discuss the pros and cons of both bispecifics and Car-T therapies. She will be joining us at 4:30pm.

Did you know you can track your myeloma using [HealthTree CureHub](#)? You can even track your myeloma from several facilities and put everything in a single place. This includes your:

- Myeloma labs (manually added or with the help of our [HealthTree Connect App](#))
- Minimal Residual Disease (MRD) status
- Myeloma genetics
- Current health and fitness status
- Prior lines of treatment and outcomes
- Side effects for each line of therapy
- Other important health information, like family history of cancer

When you create an account at any of the HealthTree Foundation programs, such as the Myeloma Coach, Myeloma Community Program (events), or HealthTree CureHub, you get access to all of the other programs using the same username and password.

An interesting article from ASH

ASH 2022: Seniors Enjoy Life with Less Dex

The side effects of dexamethasone are well known and well bemoaned by most. Insomnia, agitation, anxiety, aggression, personality/mood changes, depression, and stomach upset are just a few of the issues that have helped this steroid, commonly referred to as dex, earn its bad reputation.

Based on research presented at ASH 2022, seniors may be able to eliminate dex from their treatment after an initial 8-week period.

Dr. Salomon Manier delivered an oral presentation titled, “A Dexamethasone Sparing-Regimen with Daratumumab and Lenalidomide in Frail Patient with Newly-Diagnosed Multiple Myeloma: Efficacy and Safety Analysis of the Phase 3 IFM2017-03 Trial” ([Paper 569](#)). The research offered encouraging news that there may be a safe and effective regimen that is a better option for frail and elderly patients, prescribing dexamethasone only in the first 2 cycles of treatments, and then the treatment continues without dex.

In this phase 3 trial, 295 newly diagnosed multiple myeloma patients over age 65 with significant frailty were randomly assigned to receive a regimen of daratumumab and lenalidomide (DR) or lenalidomide and dexamethasone (Rd).

Response rates included the following:

	Dara/Rev	Rev/dex
Overall Response Rate	89%	77%
Time to reach very good partial response (VGPR)	5 months	11 months
MRD negative at 12 months	33%	18%

The results in the DR group were consistent across subgroups of age, exercise status, myeloma stage, genetics, and kidney function.

The authors concluded:

“In this phase 3 trial dedicated for frail patients with newly diagnosed multiple myeloma, a dexamethasone-sparing regimen combining daratumumab and lenalidomide demonstrates deep and rapid responses and a favorable safety profile.”

Our virtual meetings are on the Zoom platform.

Our meeting for February 21, 2023 will be from 3:30pm to 5:30pm. Michelle Lakner will be joining us at 4:30pm. Mark your calendar now not to miss this meeting.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQU2FOZ1hMUkFaRmJBc0Qzdz09>

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/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.