

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

 Meeting:
 Meetings will resume when we are allowed to gather at the address below.

 451 Junction Road
 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.

<u>Group Information:</u> Jayne Schwartz 608- 244-2120 <u>schwartzdon@sbcglobal.net</u>

Madison Multiple Myeloma Support Group website madisonmultiplemyeloma.org

Mailing Address:Wisconsin Multiple Myeloma Support Group
3309 Chicago AvenueMadison, WI 53714-1815

<u>Information Sources :</u> 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

December 2021 Myeloma Newsletter

Upcoming Meeting Speakers-

<u>Cameron Ninos, UW Pharmacist</u> will be our featured speaker for the February 15, 2022 virtual meeting. I will be taking questions in advance to start this meeting. It will be an open discussion for questions related to medications. **This will not be a forum for questions about pricing.** Cameron will present from 4:00pm to 5:00pm.

<u>Shannon Ramirez, Oncology Clinical Educator from the Janssen Pharmaceutical Company</u> will be our featured speaker for the March 15, 2022 meeting. Her presentation will be the "Shared Decision Making Deck". Shannon will present from 3:30pm to 4:30pm.

A valuable resource that you may have overlooked...the IMF InfoLine

The IMF's InfoLine is here for your myeloma-related questions and concerns. The InfoLine team consistently provides callers with the best information about multiple myeloma in a caring and compassionate manner.

800-452 CURE (2873)

US & Canada

This line continues to answer questions from newly diagnosed patients, patients 10yrs after diagnosis, 20yrs and more. If

you are starting a new drug or a new treatment protocol and have questions, they are available to help get you answers. More information is at the end of this newsletter.

Withdrawal of Farydak from FDA approval 11-30-2021

SUMMERLIN, Nev., Nov. 30, 2021 -- Secura Bio, Inc., an integrated pharmaceutical company dedicated to the worldwide development and commercialization of impactful oncology therapies, announced today that, based on discussions with the U.S. Food and Drug Administration (FDA), Secura Bio has submitted to FDA for the withdrawal of the approval of NDA 205353 for FARYDAK® (panobinostat) oral capsules. FARYDAK received accelerated approval in February 2015 for use in combination with bortezomib and dexamethasone to treat patients with multiple myeloma who have received at least two prior regimens, including bortezomib and an immunomodulatory agent. There are significant issues with toxicity and possible death.

If you took one of the booklets from our previous in-person meetings, please throw it away. This is not an option for Myeloma patients anymore.

Our virtual meetings are on the Zoom platform.

Our meeting for December 21, 2021 will be from 3:30pm to 4:30pm There is no scheduled speaker so it will be a sharing meeting for the group.

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/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.