

"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:**

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#### Information Sources:

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

Phone: 800 - 452 - 2873

Email: TheIMF@myeloma.org

Phone: 203 - 972 - 1250

Email: info@themmrf.org

Website: www.myeloma.org Website: www.multiplemyeloma.org

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

# May 2023 Myeloma Newsletter

# **Upcoming Meeting Speakers**

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

Our new support group representative from Takeda, Rebekah Tobin will be our featured speaker at the May 16<sup>th</sup> meeting. "Understanding Lab Values" will be her topic for this meeting.

The Multiple Myeloma Research Foundation has a new educational tool kit! I have requested 20 copies and will let you know when they are here. This will be helpful for newly diagnosed group members. It is titled "Your Myeloma Journey Guide".

#### **Included in the tool kit:**

- •Multiple Myeloma Treatment Overview
- Multiple Myeloma Disease Overview
- ●Caregiver Guide
- Precision Medicine Booklet
- Myeloma Booklet
- Autologous Stem Cell Transplantation Booklet
- Immunotherapy Booklet
- Patient Resource Guide

At our last group meeting, there was some discussion about making sure that you share all your concerns with your healthcare team. You may think that you are just going to "tough it out" or that it is not important enough to bring up. You don't want to complain and yet it is disruptive to your well being. A simple adjustment or an addition of a new med can make all the difference to get you through the on-going treatment. One of our members was struggling with some GI upset and the addition of a med called, Colestipol worked. Some group members are also asking their healthcare team about Florajen for similar problems. Both choices are good options and have their doctor's approval. Always make sure your doctor knows and supports any and all additions. That's important!

# Our virtual meetings are on the Zoom platform.

Our meeting for May 16, 2023 will be from 3:30pm to 5:30pm. Rebekah Tobin will be joining us at 4:00pm.

## 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 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 <a href="www.supportuw.org/give">www.supportuw.org/give</a> (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Janie Winston 608-512-6068 or email at <a href="Janie.Winston@supportuw.org">Janie.Winston@supportuw.org</a>.