



“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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Madison Multiple Myeloma Support Group website
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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

April 2023 Myeloma Newsletter

Upcoming Meeting Speakers

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

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.

During the support group meeting, there has been some conversation around IVIG. Here is an explanation of what it is all about.

Intravenous Immunoglobulin (IVIG) is a product made from antibodies collected from the plasma of healthy individuals. The antibodies are proteins that help fight infections and are part of the blood's plasma. The plasma is collected from 10,000 to 50,000 individuals with normal immune systems and is then given intravenously through a vein to help strengthen the recipient's immune system and fight infections. IVIG is used in multiple conditions, including immune

deficiencies, autoimmune diseases, and some neurological conditions. IVIG can be administered intravenously, subcutaneously, or intramuscular. For myeloma patients, IVIG is usually administered every three to four weeks at a dose of 0.4 grams per kilogram. The frequency of IVIG administration may vary based on the individual's steady state levels of immunoglobulin.

Support The Safe Step Act- IMF Advocacy works continues...

A bipartisan group of Senators reintroduced S. 652, the Safe Step Act, which helps patients access drugs more quickly when their doctors seek exceptions to step therapy. As you may know, step therapy is when a patient's insurance company requires them to try less expensive drugs before moving onto pricier options. The bill establishes a process requiring a group health plan to respond to a physician's request in a timely manner while also outlining guardrails surrounding the usage of step therapy.

Why this is important: The bill ensures that patients can access their medications more quickly when step therapy is used and that step therapy protocols do not ignore the individual needs of patients. With myeloma being such a heterogeneous and diverse condition, it is extremely important that each individual's unique medical history is taken into account.

To view more about the Safe Step Act and the other groups that support this bill, click [here](#). To contact your Senator about the bill, click [here](#). For those folks without internet access, phone your representatives and let them know of your support.

Our virtual meetings are on the Zoom platform.

Our meeting for April 18, 2023 will be from 3:30pm to 5:30pm. Dr Aric Hall is our featured speaker. He will join us at 4:30pm.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQ2FOZ1hMUkFaRmJBc0Qzd09>

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 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.