



“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)
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

November 2023 Myeloma Newsletter

Upcoming Meeting Speakers

Tom Vodicka will be our featured speaker for the December 19, 2023 meeting. Tom recently spoke at the HealthTree coaches meeting that our group member, David attended. Tom's topic of “Life and Wills” is a subject that veers off of our usual Myeloma learnings. It promises to be an interesting presentation. We will still have time for some group sharing. Mark your calendar now not to miss this meeting.

Todd Foster, Product Development Director from HeathTree will be our featured speaker for the January 16, 2024 meeting. He will present information about the Cure Hub.

Shannon Blake and Christina Nielsen from the Leukemia, Lymphoma Society (LLS) will be our featured speakers for the February 20, 2024 meeting. Christina's topics will be LLS patient and community support materials, educational programs and financial resources. Shannon's topics will include LLS research initiatives and the top funded priorities.

One of the **MMRF nurse navigators** will present at the March 2024 meeting. More info to follow.

Working on getting **Dr Aric Hall, UW Carbone Cancer Center** for the April 16, 2024 meeting.

Working on getting **Dr Zhubin Gahvari, UW Carbone Cancer Center** for the May 21, 2024 meeting. Hoping to get his presentation on Relapsed Myeloma that he shared with us at the recent Multiple Myeloma Research and Patient Care event. The Trillium Research update held October 30th.

Our condolences to the family of Steven Briggs

Steven and Jane joined our group July 2019. They attended in person meetings when their schedule allowed. When we went virtual meetings February 2020, Steven often signed in to participate. He freely shared his updates with the group and had advice for others. His Myeloma was in remission but he passed away October 27, 2023 from stage 4 lung cancer. We will miss his kind words and thoughtful advice.

Have you heard about the Spoon Theory by Christine Miserandino?

With the Holiday season upon us, it is good to remember to care for yourself. Use your time and energy wisely and try not to overextend yourself. It is a time to enjoy and be thankful. The Spoon Theory is an elaborate (detailed) story of how one friend tried to explain her journey and how to portion out her time and energy. It is an interesting read. Definitely thought provoking.

At a previous group meeting there was some discussion about the **Shingrix vaccines** and their effectiveness. Here is what the CDC says about this. (May 2023)

Two doses of Shingrix provide strong protection against shingles and postherpetic neuralgia (PHN), the most common complication of shingles.

- In adults 50 to 69 years old with healthy immune systems, Shingrix was 97% effective in preventing shingles; in adults 70 years and older, Shingrix was 91% effective.
- In adults 50 years and older, Shingrix was 91% effective in preventing PHN; in adults 70 years and older, Shingrix was 89% effective.
- In adults with weakened immune systems, Shingrix was between 68% and 91% effective in preventing shingles, depending on their underlying immunocompromising condition.

Here are three resources that our own UW pharmacists are using. Check them out for additional information to your med questions. As always, talk to your pharmacists and follow their instructions.

[Home \(oralchemoedsheets.com\)](http://oralchemoedsheets.com) oralchemomedsheet.com

[Home Page – Chemocare](http://chemocare.com) chemocare.com

[Home \(ivcanceredsheets.com\)](http://ivcanceredsheets.com)

Thank you to our group member, Peg for passing this along.

Why is Dexamethasone Used in Myeloma?

POSTED: OCT 29, 2023 HealthTree Foundation

Multiple myeloma patients (and their loved ones!) have a complicated relationship with corticosteroid [dexamethasone](#). Dex can be seen [as either the hero or the villain](#) of myeloma treatment in many circumstances. The question remains: why is dexamethasone used so often in multiple myeloma treatment, and what purpose does it serve?

Why is Dexamethasone Used In Myeloma? What Purpose Does Dexamethasone Serve in Treating Multiple Myeloma?

It is used for several reasons:

1. Dexamethasone is a powerful corticosteroid **that has anti-inflammatory and immunosuppressive properties**. In multiple myeloma, the malignant plasma cells can produce inflammatory substances contributing to the disease's symptoms and complications. **Dexamethasone can help reduce inflammation and alleviate some of these symptoms**, such as pain and swelling.
2. Dexamethasone **is frequently used in combination with other drugs**, such as proteasome inhibitors (e.g., bortezomib) or immunomodulatory drugs (e.g., lenalidomide and thalidomide), **to enhance the effectiveness of treatment**. These combinations are often more effective in targeting multiple myeloma cells and improving the overall response to therapy. **The synergy of the treatment is increased with the addition of dexamethasone**.
3. Multiple myeloma can lead to various complications, such as hypercalcemia (elevated blood calcium levels) and spinal cord compression. **Dexamethasone can be used to manage these complications** and alleviate associated symptoms.

As the majority of myeloma patients and their caregivers know, while dexamethasone (often referred to as dex) can be effective in treating multiple myeloma, it also has potential side effects.

These include:

- immunosuppression
- weight gain
- mood changes
- increased risk of infections

Talk to your oncologist and/or specialist if the side effects of dexamethasone become severe and interfere with the quality of your life. A dose reduction or switch of steroids may be appropriate.

Our November meeting will be a group share meeting. There are no scheduled speakers.

Our virtual meetings are on the Zoom platform.

Our meeting for November 21, 2023 will be from 3:30pm to 5:30pm.

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.