



“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:

Jayne Schwartz 608- 244-2120  
[schwartzdon@sbcglobal.net](mailto:schwartzdon@sbcglobal.net)

Madison Multiple Myeloma Support Group website  
[madisonmultiplemyeloma.org](http://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](mailto:TheIMF@myeloma.org)  
Website: [www.myeloma.org](http://www.myeloma.org)

Multiple Myeloma Research Foundation(MMRF)  
Phone: 203 - 972 - 1250  
Email: [info@themmrf.org](mailto:info@themmrf.org)  
Website: [www.multiplemyeloma.org](http://www.multiplemyeloma.org)

Myeloma Crowd /Health Tree Foundation  
P.O. Box 1286  
Draper, UT 84020  
[www.myelomacrowd.org](http://www.myelomacrowd.org)

## September 2023 Myeloma Newsletter

### Upcoming Meeting Speakers

**IMF Regional Director of Support Groups, Nancy Bruno** will be our featured speaker at the October 17<sup>th</sup> meeting. She will be talking about the latest research, new treatments and resources available. She is an excellent presenter so mark your calendar now not to miss this meeting.

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

Initially, there was a potential scheduling conflict but it seems that was resolved. **Dr Natalie Callander will be our featured speaker for September 19<sup>th</sup>** . She will be attending our meeting at 4:30pm. Hope to get an update on the Trillium Research presentations that are scheduled for October 30<sup>th</sup> from 9:00am to 1:00pm. More info to follow.

### “Light the Night!”

Our “Thanks” to group member Katie for putting this together for us to gather in person. Mark your calendars now not to miss this event. There will be more information coming about where to meet. Let's gather at **Light the Night**, an event hosted by the Leukemia & Lymphoma Society! It will be held at the **Henry Vilas Zoo in Madison on Thursday, October 12, 5pm**. The Myeloma Support Group is

registered as a non-fundraising team so all you have to do is sign up using the link below. No need to donate or ask for donations. It will be wonderful to see everyone in person for this inspiring event!  
<https://pages.lls.org/ltn/wi/Capital23/multiplemyelomasupportgroupmadison>

### **I am waiting for info from the LLS rep. I'll get back to you about-**

Where in the zoo should the Support Group Team meet?

- How long is the walk?
- What will parking be like?
- How long is the event?
- Are there opportunities to sit down?
- Is there food at the event?

### **From the HealthTree website- New FDA accelerated approval.**

**Pfizer announced on Monday, August 14th that their new bi-specific antibody, elranatamab, had been granted accelerated approval from the U.S. Food and Drug Administration (FDA) to treat relapsed and refractory multiple myeloma patients. Elranatamab is commercially known as ELREXFIO.**

The approval of ELREXFIO, which targets the BCMA protein found on the surface of myeloma cells, is for myeloma patients that have received at least four prior lines of therapy, including a proteasome inhibitor (such as VELCADE), an immunomodulatory agent (such as REVLIMID), and an anti-CD38 monoclonal antibody (such as DARZALEX).

This subject came up in a phone discussion with one of our group members. Thought you might find this beneficial to know the differences.

### **Understanding Relapse In Multiple Myeloma**

POSTED: AUG 22, 2023 HealthTree

#### **What Is Considered a Relapse in Multiple Myeloma?**

Relapse refers to the recurrence of active disease after a period of remission, or as we call it in myeloma, a response (when the disease is controlled or undetectable).

Two different kinds of relapses can occur in multiple myeloma.

#### **BIOCHEMICAL PROGRESSION "RELAPSE"**

The first is a biochemical relapse detected in your labs by your physician.

It's also possible that you might have noticed the trend of your labs going up because you are actively tracking them and confirmed a biochemical relapse with your myeloma specialist.

Ideally, you and your physician have both been keeping a close eye on your lab values and notice any upward trends that seem concerning. Your doctor will tell you (but ask if you're nervous!) if those lab values increase to a concerning level.

Biochemical relapses often mean that while the relapse is detectable in your labs, the myeloma has not

risen to a level that requires immediate treatment. Most people don't have symptoms (at least, any new symptoms) while experiencing a biochemical relapse.

Although biochemical relapses can be overwhelming, it is a great opportunity for you to sit down with your doctor and talk about the next steps. Make sure that you are open with your doctor about your personal philosophy.

If the treating team is ok with it, would you rather watch and wait? If you're anxious to get treated again, is your doctor on the same page?

You can also discuss what treatment options are available to you. Consider joining a clinical trial that feels right to you.

## CLINICAL RELAPSE

This is what we typically call a "relapse" in the cancer world. The myeloma has escalated quickly, new symptoms are arising, perhaps new plasmacytomas or lesions are forming, and the pain is returning.

This usually requires treatment right away, so hopefully you have been speaking with your doctor about the next treatments and steps and what you think would be right for you moving forward.

Our virtual meetings are on the Zoom platform.

Our meeting for September 19, 2023 will be from 3:30pm to 5:30pm.

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](mailto: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](http://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](mailto:Janie.Winston@supportuw.org).**