



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

Meeting: **In person meetings will resume when we are allowed to gather at the address below.**

~~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.~~

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)

### December 2022 Myeloma Newsletter

Upcoming Meeting Speakers

No speakers are scheduled for the December 2022 meeting. Working on speakers for 2023.

Michelle Lakner, Nurse Practitioner will be speaking at our February 2023 meeting.

Will be contacting our new support group representative from Takeda for a presentation in 2023.

A big Thank You to Pamela Wilson for her generous donation to our support group. It will be used to offset the cost of preparing the newsletter and the postage needed to send the newsletter and booklets to our newest members. It is appreciated.

This is a subject that comes up in group meetings from time to time but doesn't get the attention it deserves. Bisphosphonate therapy can be valuable. Here is a brief summary of Dr. Durie's blog.

### **From the IMF (International Myeloma Foundation)**

Has the management of bone disease in myeloma changed? Are there new treatments or is the use of bisphosphonates—using Aredia® or Zometa®—still the standard of care recommendation?

The answer is yes. Those are the primary recommendations.

Bisphosphonates limit bone destruction. They attack the osteoclasts that can destroy the bone. And so, they are useful in the prevention of ongoing bone issues.

At the start of treatment, it is important to have a full dental evaluation. The reason is that if you have dental issues, this can be a focal point for the development osteonecrosis of the jaw—a destructive process triggered at the site of areas of bone damage at the bottom of your teeth.

It is important to have a dental evaluation, to have any issues taken care of before you start bisphosphonate therapy, and to keep good dental care during treatment. Once treatment is started, it should be continued monthly with Aredia or Zometa for two years—this is the standard recommendation.

Many patients who are diagnosed with myeloma these days do not have significant, active bone pain or bone destructive problems. And so, it's up to the discretion of the treating doctor to decide to reduce the frequency of the monthly infusions within those two years.

After two years, the general recommendation is to stop therapy. However, if a patient has significant ongoing active bone problems, then at the discretion of the treating doctor, it may be that perhaps less frequent use of Aredia or Zometa can be considered.

Now, an alternative to the bisphosphonates is a newer agent called Denosumab—XGEVA® is the commercial name. And this is a monoclonal antibody that can be shot once a month and it's an alternative to bisphosphonate therapy. It's primarily recommended for patients who have kidney problems, but it can be considered across the board.

The BOTTOM LINE for bone treatment: Yes, bisphosphonates are still the main recommendation with Xgeva as a backup therapy, particularly for patients who may have kidney issues.

### **From a previous meeting about the HealthTree group**

For those folks who do not have internet access, your public libraries may be able to help.

Formerly the Myeloma Crowd, the HealthTree website has many interesting features. There is a Patient Portal and a Twin Search. This allows you to enter your data and “Find Your Twin”. You are able to find someone with similar disease using their -Twin Machine™ Tool

Use Twin Machine™ technology to find, connect and chat with other patients just like you. See your twins' treatments and outcomes, find those that lived the longest with myeloma and learn what contributed to their success.

Another great option is to view the Myeloma University. Online organized curriculum for you. There is also an option to connect with a Myeloma coach and Podcasts with the experts

Our virtual meetings are on the Zoom platform.

Our meeting for December 20, 2022 will be from 3:30pm to 5:30pm. There are no scheduled speakers so this meeting will be a group share.

#### Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQ2FOZ1hMUkFaRmJBc0Qzdz09>

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).