



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

Meeting: **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)

## December 2020 Myeloma Newsletter

### Special note...

I would like to thank everyone who shared their special stories about how Don has touched them. Although reading them was hard, it also was very comforting to know that he did reach out to so many of you. Stories that I never heard or knew of. Thank you for those cards and emails. His “Doctor Don” lessons will forever be remembered. But don't try them!

Thank you to all that honored him by contributing to the Trillium Research Fund. Don and I have always believed that this research was so valuable for everyone diagnosed with this disease.

Last month I was contacted by a new organization called **Mission Myeloma**. Their president, Shaya Swenson sent me some information that I would like to share with you. (This group is primarily a Wisconsin resource.) They offer financial grants to multiple myeloma patients with a permanent residence in Wisconsin. The application is simple and can be downloaded from their website under “Financial Grants” <https://missionmyeloma.org/financial-grants>

Their goal is to provide support and resources for Wisconsinites diagnosed with multiple myeloma while also funding research for a cure. Learn more about multiple myeloma symptoms, find out how we provide [financial assistance for cancer patients](#) and [visit our FAQ page for additional multiple myeloma resources](#).

**Study Results Show Selinexor (XPOVIO) with Bortezomib and Dex to be a Convenient and Effective Triplet Combination** Selinexor (XPOVIO) was approved by the FDA in 2019 to be used with dexamethasone for patients who had relapsed five types of myeloma treatment. The BOSTON study results published in The Lancet show that selinexor, weekly bortezomib (Velcade) and low-dose dexamethasone is an effective combination for multiple myeloma patients who have received 1-3 lines of prior therapy.

The BOSTON study, performed at 123 sites in 21 countries, included 402 patients. Patients were split into two groups evaluating once-weekly selinexor in combination with once-weekly bortezomib (Velcade) and low-dose dexamethasone (SVd) compared to standard twice-weekly Velcade plus low-dose dexamethasone (Vd) in patients with multiple myeloma who have received one to three prior lines of therapy. This is the first trial to evaluate a once-weekly bortezomib schedule in relapsed multiple myeloma compared to a twice weekly comparator Vd arm.

Median progression free survival was 13.93 months with the selinexor/bortezomib/dex combination vs. 9.46 months with bortezomib/dex. Peripheral neuropathy of grade 2 or higher was less frequent when selinexor was added (21%) compared to the doublet combination (34%). The mortality rate during the study was 24% in the selinexor/bortezomib/dex arm vs. 30% in the bortezomib/dex arm.

The FDA accepted a New Drug Application earlier this year for selinexor use in patients with only one prior line of therapy.

Additional clinical trials such as the STOMP trial are underway to examine selinexor with other standard myeloma therapies.

This once-weekly (all oral) option may be a new, effective and convenient treatment options for patients at earlier relapse.

By Jennifer Ahlstrom | Posted - Nov 13th, 2020 Myeloma Crowd News

**Myeloma Crowd Round Table Interactive Webcast**  
**Saturday, December 19, 12:00-2:00 pm (EST)**  
**Understanding, Managing and Minimizing Side Effects of**  
**Treatment**

**Register Today**

Side effects of myeloma treatment often seem worse than the disease itself. In many cases, however, they can be anticipated and minimized. In others, it is important to be able to listen to your body and recognize them before they have a negative effect on day-to-day living. Caregivers also need to be aware and understand symptoms. Side effects can be associated with every phase of treatment. With newly approved medications, side effects do not appear until it has been used in many patients.

Craig Hofmeister, MD, MPH, from Emory University's Winship Cancer Institute and Suzanne Lentzsch, MD, PhD, from Columbia University's Irving Comprehensive Cancer Center will discuss how to recognize, mitigate and possibly avoid side effects due to myeloma treatment. Both will participate in a question-and-answer session available exclusively for registered viewers. If you have any questions, please contact Greg Brozeit at [greg@crowdcare.org](mailto:greg@crowdcare.org) or call or text 330-990-1090.

Wisconsin Multiple Myeloma Support Group

Tue, Dec 15, 2020 3:30 PM - 4:30 PM (CST)

**Please join my meeting from your computer, tablet or smartphone.**

<https://global.gotomeeting.com/join/739441677>

**You can also dial in using your phone.**

United States (Toll Free): [1 866 899 4679](tel:18668994679)

United States: [+1 \(571\) 317-3116](tel:+15713173116)

**Access Code:** 739-441-677

New to GoToMeeting? Get the app now and be ready when your first meeting starts:

<https://global.gotomeeting.com/install/739441677>

The invitation will allow you to join the meeting from your computer, tablet or smartphone. It is important to not to telephone in if you have already clicked on the link to sign in on your computer, tablet or smartphone. The two audios will compete with each other causing a continuous loop for sound. It resembles screeching like you dialed a Fax phone number instead of the right one. An awful noise! If your desktop computer does not have the audio activated, you will have to telephone in.

If you don't have a webcam on your computer, you probably don't have a mic either and should

telephone in.

No computer, no problem. **Use toll free 1-877-309-2073 when dialing in.** There are limitations to the number of participants when you use the other toll free number given in the invitation.

It is very important that we use conversational courtesies. Let's make sure that we don't talk over other people's conversations. It is going to be hard but I know we can do it.



**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 specialists 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 Daniel Rosen at (608) 264-5437 or email [curecancer@supportuw.org](mailto:curecancer@supportuw.org).