



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

Meeting: Tuesday October 15, 2019 3:30pm – 5:30pm  
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)

Upcoming Meeting Speakers... Mark your calendars now!

Dr Shannon O'Mahar will be our featured speaker for the December meeting. She may be presenting 2019 ASH conference highlights.

Dr Natalie Callander will join us for the October meeting. She will be here at 4:30pm to present information from the many conferences that she attends. There will be time for Q & A.

A big “Thank You!” to group member Antje for her generous contribution to our support group. It is appreciated and will go towards the expenses of the newsletter printing and mailing.

At the recent **Multiple Myeloma Patient and Caregiver Symposium**, I attended a breakout session “Financial Help and Social Services”. I was curious as to the role of the hospital social workers. Social workers can be a resource for what community resources you might have available. They will help with Advance Directives, POA for Health Care and hospital based financial assistance programs.

They can also be a resource for current insurance questions, Market Place plans, Medicare, Medicaid, Cobra, etc. They can also help you find a support group. One helpful financial site that was mentioned was the Pan Foundation. <https://panfoundation.org>. Or go direct to the Pan Fund Finder at <https://fundfinder.panfoundation.org>.

One of their most important duties is to help you apply for social security disability if needed and to get that approval. Work with them to apply because they can ensure proper wording to make sure the you are not denied your benefits. They will gather the doctor's documentation and do that paper work for you. Sometimes terminology will be a deciding factor in your benefit being denied. Words such as “remission and maintenance” can be mistaken for the ability to resume full time employment. After transplant, you may be in remission but you may not be strong enough to resume working. Fatigue and overall body strength may take months to stabilize.

From the IMF website....

Multiple myeloma drugs fall into various drug classes, proteasome inhibitors (PIs), immunomodulatory drugs (IMiDs), alkylating agents, corticosteroids, histone deacetylase inhibitors (HDACs), bisphosphonates, and monoclonal antibodies (MAbs). The following chart breaks down these medications according to their drug class. Some of the drugs you may already know about and others may be new to you.

Drug Class	Name	Abbreviations	Brand
Proteasome inhibitors	ixazomib	I	Ninlaro®
	carfilzomib	cfz, car, K	Kyprolis®
	bortezomib	btz, bor, V	Velcade®
Immunomodulators	pomalidomide	pom, P	Pomalyst®
	lenalidomide	len, R	Revlimid®
	thalidomide	thal, T	Thalomid®
Alkylating agents	melphalan	mel, M	Alkeran®, Alphalan®
	cyclophosphamide	CTX, Cy, C	Cytosan®
	bendamustine		Treanda®
Corticosteroids	dexamethasone	D, d, dex, DXM	Decadron®
	prednisone	pred, P	Delatsone®
	methylprednisolone	none yet	Medrol®
Histone Deacetylase Inhibitors	panobinostat	none yet	Farydak®
	denosumab	none yet	Xgeva®
Bone-modifying agents	zoledronic acid	zol	Zometa®
	pamidronate	pmd	Aredia®
Monoclonal antibodies	daratumumab	dara	Darzalex®
	elotuzumab	elo, E	Empliciti®
XP01 inhibitor	selinexor	none yet	Xpovio®

You can learn more about them from the IMF website at [www.myeloma.org](http://www.myeloma.org)

**At our September meeting, we celebrated our 20<sup>th</sup> year anniversary of the Madison Support Group.**

Thank you everyone for the cards and gifts. Your kind words meant a lot to Don and I. We have been forever grateful for this support group and the many wonderful people to cross the threshold to attend a meeting. And, the wonderful people on our newsletter email listing too. I appreciate hearing from you.

Thank you to all who helped with the cake, coffee and treats. Thank you to those who wrote to the group to express their gratitude and well wishes. Thank you to our special guests... Judge Dan, Chief Mike and Conner Koval.

I hope you enjoyed yourself as much as I did. And, “No” Allen we will not do this every month! Honestly, I felt the same way. It was a wonderful gathering to celebrate such a milestone. I wish that “feeling” for all the meetings to come.

Hope to see you soon.  
Jayne

**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).

**New information!**

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).