



“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 August 20, 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:

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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!

**Our Myeloma Support Group will be recognizing a milestone 20yrs in September. No speaker is planned. Leaving the time open for us to celebrate! If you are group member but have not attended in a while, mark your calendar for this anniversary celebration and stop by to visit.**

Dr Natalie Callander will likely join us for the October meeting.

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

Mark your calendars for the **3<sup>rd</sup> Annual Myeloma Patient and Caregiver Symposium** in Pewaukee, WI Saturday, September 28<sup>th</sup>. This is a great conference and you will not want to miss it.

I will be recapping the Cancer Psychology presentation and coping strategies in the next newsletter.

Our meeting speaker for August will be Kelly Sidorowicz, IMF Regional Director, Support Groups. She will join us at 3:30pm and will have a Q & A time available.



Kelley Sidorowicz joined the IMF's Support Group team in 2019 after previously being part of the Advocacy team since 2016, working on federal and state policy issues as well as helping the IMF to grow our grassroots network. Previously, she worked in the health and wellness community as a certified health and wellness educator, personal trainer, and yoga instructor. Kelley holds a Bachelor of Science degree in Exercise Physiology from Frostburg State University. She resides in Southern Maryland.

**Wisconsin State Journal Friday, August 9, 2019 - Medicare to Cover Gene Therapy.**

Medicare said that it will cover CART-T cell therapies for certain types of lymphoma and leukemia. CART-T uses gene therapy to turbocharge the patient's immune system cells, reprogramming them to harbor a "receptor" that zeroes in on cancer and to grow hundreds of millions of copies. These revved up cells are returned to the patient's bloodstream and can continue to fight cancer for months and years. Side effects can be severe. Studies have shown the treatment to be highly effective against certain cancers. Researchers are working to add more types to the list.

**Lots of interest for this one...** What is GSK 2857916, also known as belantamab mafodotin? Quote from Dr Durie, "The GSK product is an important monoclonal antibody which targets BCMA, which is the B-cell maturation antigen on the surface of myeloma cells. It is a unique product in that it is combined with a drug, it is called a drug conjugate. And, this is very important because when the antibody binds, the drug conjugate is imported into the myeloma cell and leads to more complete destruction of the myeloma. And so, this agent has now been given a name, a very long name, belantamab mafodotin. GSK folks have decided to abbreviate this name to "Bela", very similar to "Dara" for daratumumab. And so, you're going to be hearing this agent referred to as "Bela."

Results show that this monoclonal drug conjugate has a 60 percent overall response rate in patients with relapsed/refractory myeloma. And this is incredibly important because this is an off the shelf product against this BCMA target, which is what is the target for CAR-T cells, BiTEs, and other much more complicated and expensive therapies.

There has been a rapid approval designation from the FDA as well as a prime designation by the EMA. With any good luck, the results of the ongoing DREAMM II, part II study, will lead to submission to the FDA, and hopefully, approval later this year or early next year.

**Brand new booklet from the IMF Educational Series.... Understanding Peripheral Neuropathy in Myeloma.** This can be viewed online and is very well written. Very comprehensive and will expand what you may already know about this subject. Bet you didn't know about "Pickle Juice"? See page 13.

**Our group member, Bashir Nasserjah will be doing "The Ride",** Sunday, September 22, 2019 Madison, WI. To support him and all the riders, go to [www.theridewi.org](http://www.theridewi.org). This ride fundraiser will support the cancer research at the UW-Madison.

Thanks to our group members- Rob and Peg....

Dr Shannon O'Mahar shared a Sloan Kettering website that she uses frequently to research information about Herbs and Supplements that her patients are asking about. Memorial Sloan Kettering CC, "Search About herbs"

Google: mskcc about herbs

You will find all about potential drug interactions, etc. Information you need to know if you are considering any herbs or supplements.

**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).