



“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 April 18, 2017 3:30pm – 5:30pm**  
**451 Junction Road**  
**UW West Clinic Room 1287**  
**Enter the clinic... proceed left past the vending area... turn left again and conf. room 1287 is the last one on the left.**

**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

**More Information:**  
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) 203 - 972 - 1250 Email: [info@themmr.org](mailto:info@themmr.org) [www.multiplemyeloma.org](http://www.multiplemyeloma.org)

**Upcoming meeting speakers:**

Working on a pharmacy speaker for May or June meeting.  
Dr Natalie Callander will be our October meeting speaker. She will be here at 4:30pm.

Sue Enright, Midwest Regional Director, Support Group liaison from the IMF will be presenting at our April meeting.

**Our condolences.....**

Our group member, Dan Sackash passed away on March 3, 2017. Dan joined our group April 2015. He attended meetings when he could and was an active contributor to our conversations. We will miss him. Our thoughts are with his family.

**“Managing Peripheral Neuropathy, A Guide For People With Myeloma” from Myeloma Australia.**

If you get a chance to read this one, it is worth your time. Very interesting and I learned much more about peripheral neuropathy. It is attached for those folks that have internet capability. The document is 32 pages so I am not able to send printed copies. Remember, your public libraries can help you access this site.

**Ever want to be a rock band groupie?** Our group member, Joe Ripp is just finishing up his 3rd musical CD with 14 original songs. He intends to sell the CDs for \$11.99 with 100% of any monies over the production cost to go to UWCCC Trillium Fund. He plans to have a sample CD that we can listen to at our next meeting. His goal is to be able to donate at least \$8.00 from every CD to UWCCC Trillium Fund. He does not want any income from this endeavor and intends to give a tax write off to anyone purchasing a CD. More information to follow.

**Wisconsin State Journal, April 1, 2017 Collectar Biosciences tests Myeloma Drug**

Collectar says it is starting phase- two clinical trials on a compound to treat Myeloma patients and other blood cancers. 80 Patients at up to 15 centers across the U.S. will receive one dose of Collectar’s CLR-131 with the possibility of a second dose about three to six months later. Dexamethasone is given for up to 12 weeks too. Results of the study are expected in the

second half of 2017. “The prospect of extending patient survival with one dose or two continues to drive a high sense of urgency for all involved”, said Jim Caruso, Collectar’s president and CEO.

### **SLiM Crab criteria**

Dr. Joshua Richter, Clinical Assistant Professor at Rutgers and practicing hematologist/oncologist at the John Theurer Cancer Center at the Hackensack University Medical Center explains **SLiM Crab**.

One question that I am frequently asked is, what is the difference between smoldering myeloma and multiple myeloma? Now, for years, the classical definition of myeloma in general has been patients who have greater than either 3 grams of paraprotein in the blood and/or greater than 10% clonal plasma cells in the bone marrow. When either of these situations is met, the patient has multiple myeloma. They only go from smoldering to symptomatic myeloma when they have one of the CRAB symptoms. CRAB stands for: C high calcium, R renal dysfunction, A anemia, and B bony lytic lesions.

Now, this has been the definition for many years that has separated smoldering myeloma from symptomatic multiple myeloma. However, it has been noted for some time that there are certain patients who are so likely to progress from smoldering to symptomatic that they ought to be treated. In the *Lancet Oncology* in 2014, S. Vincent Rajkumar, et al., published a paper redefining what is smoldering and what is symptomatic myeloma, and a new group of patients emerged that were classically smoldering and now fit criteria to be treated. The CRAB criteria have been updated to what we call a SLiM CRAB:

As relates to Smoldering Myeloma...The CRAB criteria have been updated to what we call a SLiM CRAB:

- S stands for 60%: those patients who have 60% or more clonal plasma cells in the bone marrow were so likely to progress that they ought to be treated and are now classified as symptomatic myeloma
- Li stands for light chains: those patients with a kappa-to-lambda or lambda-to-kappa ratio of greater than 100 are so likely to progress to needing treatment that they should be treated at the time of diagnosis
- M stands for MRI: patients with more than one focal lesion on MRI now have transitioned from smoldering myeloma to symptomatic disease warranting therapy

So, CRAB has become SLiM CRAB and has helped us to better understand those patients who need therapy and those who do not. November, 2016

**Florajen 3** is a probiotic that we have talked about in our group meetings. **It is important that you consult with your oncologist/doctor if you are considering using this product.**

Probiotics contain different types of micro-organisms such as yeast (*saccharomyces boulardii*) and bacteria (such as *lactobacillus*, *bifidobacterium*). Micro-organisms (flora) are naturally found in the stomach/intestines/vagina. Some conditions (such as antibiotic use, travel) can change the normal balance of bacteria/yeast. Probiotics are used to improve digestion and restore normal flora.

Probiotics have been used to treat bowel problems (such as diarrhea, irritable bowel), eczema, vaginal yeast infections, lactose intolerance, and urinary tract infections. It has been helpful to several people who were struggling with diarrhea. Check with your doctor.

### **March was Myeloma Awareness Month!**

Our thanks to group member, Mary Polancih for requesting a proclamation from Governor Scott Walker. The proclamation declares March 2017 as Multiple Myeloma Awareness Month; signed by both the governor and Douglas LaFollette, Secretary of State.

Below are some updates compliments of the IMF. If the links are not "clickable", please copy and paste the web address into your browser and hit Enter.

#### Ask Dr Durie Video

- March 16: Is a low white blood count common in smoldering multiple myeloma?

<https://www.myeloma.org/videos/low-white-blood-cell-count-common-smoldering-multiple-myeloma-0>

#### Dr. Durie's Blog

- March 1: CNN profiles Black Swan Research Initiative's innovative istopMM project.

<https://www.myeloma.org/blog/dr-duries/cnn-profiles-black-swan-research-initiative's-innovative-istopmm-project-and-asks->

- March 22: Watch CNN interview highlighting IMF-funded myeloma research project in Iceland.

<https://www.myeloma.org/videos/watch-cnn-interview-highlighting-imf-funded-myeloma-research-project-iceland>

- **March 23: Living Well with Myeloma: Novel Agents and Clinical Trials; What Patients and Caregivers Need to Know. This one reported to be very good!**

<https://www.myeloma.org/videos/living-well-myeloma-novel-agents-clinical-trials-2017>

- March 30: Free Webinar: Addressing concerns on the recent lack of funds for co-pay assistance.

<https://www.myeloma.org/videos/free-webinar-addressing-concerns-recent-lack-funds-co-pay-assistance>

Myeloma Matrix 2.0: Smart Search

- Here is a link to the Myeloma Matrix 2.0!

<https://www.myeloma.org/matrix>

The following co-pay assistance foundations are now open to myeloma patients who receive drug coverage through Medicare and who meet eligibility requirements: **As of 4/10/17**

#### **Healthwell Foundation**

tel: 800-675-8416

website: [healthwellfoundation.org](http://healthwellfoundation.org)

#### **LLS Co-Pay Assistance Program**

tel: 877-557-2672

website: [lls.org](http://lls.org)

#### **Patient Advocate Foundation**

tel: 800-532-5274

website: [www.patientadvocate.org](http://www.patientadvocate.org)

*up to \$10,000*

**Save the dates.....**

**CancerCare presents..."Progress in the Treatment of Multiple Myeloma". Thursday, May 18, 2017, 1:30 – 2:30 pm, Eastern Time [Register Now](#). Registrants can listen in live over the phone or online as a webcast.**

Upcoming summer fund raiser....

Save the date for “On Course for a Cure”, a golf tournament to raise money for the Trillium Fund for Multiple Myeloma Research at UW Carbone Cancer Center. The event will be held at noon on Monday, August 7, 2017 at Blackhawk Country Club, 3606 Blackhawk Dr., Madison, WI, 53705. Golf will be followed by a program and dinner. For more information, please contact Katie Dowling-Marcus at [kdowlingmarcus@gmail.com](mailto:kdowlingmarcus@gmail.com).

**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”.

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