



“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 March 19, 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

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
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Upcoming Meeting Speakers... **Mark your calendars now!**

Kelley Sidorowicz, IMF Support Group Regional Director will be our featured speaker at the August meeting.

Working on getting the Celgene representative back for another meeting. More info to follow.

Made contact with the UW Cancer Psychology department for a guest speaker. More info to follow.

Don't forget the Myeloma educational event March 23, 2019. Conference is at the Four Points Sheraton Milwaukee North Shore. 8900 North Kildeer Court. Call 1-866-508-6181 to register.. Conference is sponsored by Takeda.

Dr Aric Hall will be our guest speaker for the March meeting. He is a group favorite so mark your calendars now. His “Question and Answer” session begins at 4:30pm.

Our February speaker, Dr Sara Christensen-Holz presented some valuable information about Managing Neuropathy and Balance issues. These are common problems for many patients. She gave us some exercises to practice. We all did very well. Exercises were simple but have a positive impact on our well being.

In her outline, she also spoke to Fatigue. There are different types of fatigue.

Peripheral fatigue is caused by the nerves and muscles. You feel very tired doing physical activities and it takes you a while to recover. Your muscles feel heavy or weak. You need to take frequent rest breaks and may feel profoundly tired after work or exercise.

Central fatigue is caused by changes in the brain. It may cause you to feel foggy and have poor memory. It may be made worse by exercise or exertion but may be present even when you are not physically active.

Central exhaustion syndrome is sudden, severe exhaustion. It may last an hour or longer. This is usually time limited. Patients with “Chemobrain” may become exhausted after reading and other nonphysical activities.

Take away here is to rest when your body tells you to. Keep as active as you can without putting yourself at risk. Practice the balance exercises!

Want to know more about your lab tests? www.labtestsonline.org is a simple yet readable way to learn more. Also, Takeda put together a great resource.... “Understanding Your Myeloma Lab Tests”. I am requesting printed copies. Outline is attached to email copies of this newsletter.

Co Pay Assistance Programs Update As of March 5, 2019:

The **Healthwell Foundation** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **Healthwell page**.

The **Patient Advocate Foundation (PAF)** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit **PA page**.

However, many other co-pay assistance programs are still **unable** to assist patients. If you have an existing grant, please check its status with that co-pay foundation. Links provided below:

[CancerCare](#), [Good Days](#), [LLS](#), [Patient Access Network Foundation \(PANF\)](#)

If you are in need of co-pay assistance, we also encourage you to contact the patient support programs of the drug manufacturers directly:

Celgene

- Thalomid, Revlimid, & Pomalyst
- Celgene patient support web portal

Takeda

- Ninlaro 1Point Program
- Velcade Support

Amgen

- Kyprolis
- Amgen Assist 360 Program

Janssen

- Darzalex
- Janssen CarePath Program

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.

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”. Sean Lynch Director of Development UW Carbone Cancer Center University of Wisconsin Foundation 1848 University Ave Madison, WI 53726 (608) 422-1714 cell sean.lynch@supportuw.org

www.mycarbhone.org has been established as an easier way to contribute. Check it out!