



“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 June 18, 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
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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.

Our Myeloma Support Group will be recognizing a milestone 20yrs in September. No speaker is planned. Leaving the time open for us to celebrate!

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 3rd Annual Myeloma Patient and Caregiver Symposium in Pewaukee, WI Saturday, September 28th. This is a great conference and you will not want to miss it. More info to follow.

Erin Costanzo, PH. D. UW Cancer Psychology department will be our featured speaker for the June meeting. Mark you calendar now!

What I learned about drug pricing ... May 2019 AARP Bulletin

In March, AARP launched “Stop Rx Greed”, a national campaign to persuade federal and state lawmakers to curb rising prescription prices.

Did you know:

- We are the only industrial nation in the world whose government doesn't bargain with drug makers over pricing.
- To encourage innovation and allow drug companies to recoup their expenses, the federal government grants 20 year patents on new drugs that give companies exclusive right to market the medication. When that time is running out, drug companies can “evergreen” their patents, usually by re-purposing or reformulating the medication. These strategies, such as changing the dosing schedules add as many as 20 more years to their monopoly periods. Extending the time before less expensive generics from entering the market.
- In order to justify high drug prices drug companies do add in the capital costs of what that research/development money would have yielded if invested rather than tied up bringing the new drug to market. Reality is that virtually off of today's new drugs have roots in government funded research at the National Institute of Health or leading academic centers across the country.

What can we do? Attached is a quick letter put together to make it simple to make contact with your government representatives. It is a first place to start. You can make a difference!

Available Funding

The Leukemia & Lymphoma Society (LLS) *Patient Aid Program* provides financial assistance to blood cancer patients in active treatment. Eligible patients will receive a one-time \$100 stipend to help offset expenses.

As a non-profit organization, we rely on the generosity of our sponsors. Program continuation is dependent on the availability of funds and the program could be modified or discontinued at any time if funding is limited or no longer available.

Eligibility Requirements

To be eligible for the Patient Aid Program, the patient must:

- Be a United States citizen or permanent resident of the U.S. or Puerto Rico
- Have a blood cancer diagnosis
- Be in active treatment, scheduled to begin treatment, or being monitored by their doctor

How to Apply

LLS offers patients, caregivers, and healthcare providers two easy ways to apply:

- **By Phone:** 866-446-7377
Monday to Friday, 8:30 am. to 5:00 pm. ET
- **Online:** [Online portal](#)
24/7, Available in English only

Required Information for Application:

- The patient's Social Security Number and date of birth
- If patient is a minor (under the age of 18), patient AND guardian's Social Security numbers and date of birth are required.
- The patient's blood cancer diagnosis

IMF presents: Dr Durie's Post ASCO/EHA/IMWG teleconference

Thu, 06/27/2019 – 06:00pm CST

Learn more about current trends in myeloma treatment and research with this update from three major medical meetings held in May and June 2019.

Dr. Brian G.M. Durie will explain what's new and exciting from:

- American Society of Clinical Oncology (ASCO),
- European Hematology Association (EHA), and
- International Myeloma Working Group Summit (IMWG).

You won't want to miss this free IMF teleconference followed by a Q&A session! Save the date, register now on the IMF website.

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.

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 (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Daniel Rosen at (608) 264-5437 or email curecancer@supportuw.org.