



“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 September 15, 2015 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)

**Mailing Address:** Wisconsin Multiple Myeloma Support Group  
3309 Chicago Avenue  
Madison, WI 53714-1815

**More Information:**

International Myeloma Foundation (IMF)	Multiple Myeloma Research Foundation (MMRF)
Phone: 800 - 452 - 2873	203 - 972 - 1250
Email: <a href="mailto:TheIMF@myeloma.org">TheIMF@myeloma.org</a>	<a href="mailto:info@themmr.org">info@themmr.org</a>
Website: <a href="http://www.myeloma.org">www.myeloma.org</a>	<a href="http://www.multiplemyeloma.org">www.multiplemyeloma.org</a>

**Upcoming speakers**

- Dr Natalie Callander to speak at the October meeting. She will present at 4:30pm. Mark your calendars now!
- Still waiting to hear from the UW Sleep Clinic. Hoping to get one of the doctors to come to present information about the importance of good sleep and being well.
- Have made contact with the UW Kidney clinic for a speaker. Still waiting to hear from them too.
- December meeting speaker will be Peggy Wellmann, Clinical Nurse Educator Takeda Oncology. Peggy will present “Understanding Lab Values”.

**Our August meeting speaker, Dr Lori DuBenske, PhD UW Psychology presented “Protection, Guilt and Other Patient-Caregiver Traps”.** Dr Lori shared that the patient and caregiver both adjust to the illness in the same biopsychosocial way. Physical, social cultural and psychological considerations contribute to the overall well-being of both people. Both want what is best for their loved one. Many shy away from the problems of the “illness” because they don’t want the other party to be upset. They are confused because the problems have no easy or obvious solutions. Communication becomes difficult or non-existent which will lead to feelings of distance and a lack of intimacy. What’s the strategy? Communicate openly even if it is hard. It is a step toward solving problems and feeling closeness from working together. Being that “battle buddy” will bond you together and increase closeness. “Protecting” too much can become too restrictive and cause feelings of being trapped or nagged. Both people can become resentful and misunderstood. The sources of guilt are different for both parties. For the patient- changes in relationship because of the illness, being a burden and not being around. For the caregiver-their own health, negative feelings of burdens, not providing all possible kinds of support to their loved one and leaving their loved one behind. Strategy to overcome: separate the guilt and remorse from the sorrow. Not an easy task. Stop saying you are sorry for things that are not your fault. Reframing your conversations with “I wish” will avoid the “I’m sorry” trap.

**It's not too late! Register now for Saturday's conference.**

**Leukemia Lymphoma Society 13th Annual Multiple Myeloma Conference**

Date: Saturday September 12, 2015

Location: Country Springs Hotel-Pewaukee, WI

Conference is free to attend and we welcome anyone impacted by a myeloma diagnosis: patients, caregivers & families, and healthcare professionals!

Register [Here!](#) For those folks without internet access, call 262-785-4274. More info to follow. This is a conference worth attending!

**July 27, 2015 FDA Grants New Indication for Kyprolis in MM by Marie Rosenthal**

The FDA has granted a new indication for the combination of carfilzomib, lenalidomide and dexamethasone for patients with relapsed multiple myeloma (MM) who have received one to three prior lines of therapy.

The new indication was based on a demonstration of improved progression-free survival (PFS) in the multicenter, open-label ASPIRE (CARfilzomib, Lenalidomide, and Dexamethasone versus Lenalidomide and Dexamethasone for the treatment of Patients with Relapsed Multiple Myeloma) trial, which enrolled 792 patients with relapsed or refractory MM after one to three lines of prior therapies. The patients were randomized to receive lenalidomide and dexamethasone with or without carfilzomib for 18 cycles. Lenalidomide (Revlimid, Celgene) and dexamethasone were continued thereafter until disease progression.

The study showed that patients treated in the carfilzomib-lenalidomide-dexamethasone (KRd) arm lived 50% longer (8.7 months) without disease progression compared with patients treated with lenalidomide and low-dose dexamethasone (Rd) alone.

Carfilzomib is an epoxyketone proteasome inhibitor that binds to the constitutive proteasome and immunoproteasome, triggering apoptosis.

“What is important for physicians and patients to know about this drug is that adding a third drug, carfilzomib, increases progression-free survival, increases the overall response rate and triples the number of patients with complete response,” explained Dr. Stewart. “This should change the practice of physicians, since it has been the standard to use two drugs instead of three,” he added.

MM is the second most common hematologic cancer and nearly 96,000 individuals in the United States have an MM diagnosis. The estimated number of new cases of MM in 2014 was more than 24,000.

**\$\$\$ Financial Help for Cancer Patients \$\$\$**

**The Philadelphia Inquirer** recently had an article titled “*Finding Help for the High Costs of Cancer Care.*” The link is:

[http://www.philly.com/philly/business/20150608\\_Finding\\_help\\_for\\_the\\_high\\_costs\\_of\\_cancer\\_care.html](http://www.philly.com/philly/business/20150608_Finding_help_for_the_high_costs_of_cancer_care.html). Following is the list of resources cited in the article:

**Cancer.net** maintains a list of organizations that help patients financially ([www.cancer.net](http://www.cancer.net)).

**The Cancer Financial Assistance Coalition** ([www.cancerfac.org](http://www.cancerfac.org)) is a group of national organizations that provide financial help.

The nonprofit **CancerCare** provides limited financial assistance to people affected by cancer ([www.cancercare.org](http://www.cancercare.org)). It also has a foundation to help fund copays, the **CancerCare Patient Assistance Foundation** (call 866-552-6729 or visit online at [www.cancercarecopay.org](http://www.cancercarecopay.org)).

The **HealthWell Foundation** (800-675-8416 or [www.healthwellfoundation.org](http://www.healthwellfoundation.org)) similarly provides financial assistance to cover copayments, premiums, and deductibles for certain medications and therapies.

**Partnership for Prescription Assistance** (888-477-2669) helps qualifying patients who lack prescription-drug coverage obtain the medications they need.

**Needy Meds** ([www.needymeds.org](http://www.needymeds.org) or 800-503-6897) offers information on companies assisting those who can't afford medication.

**The Patient Access Network Foundation** (866-316-7263 or [www.panfoundation.org](http://www.panfoundation.org)) assists patients with out-of-pocket costs associated with their treatment.

**Patient Services Inc.** (800-366-7741 or [www.uneedpsi.org](http://www.uneedpsi.org)) assists with insurance premiums and copayments for people with chronic diseases.

**RxHope.com** (877-267-0517 or [www.rxhope.com](http://www.rxhope.com)) helps patients obtain free or low-cost prescription medications.

**The Assist Fund** (855-845-3663 or [www.assistfund.org](http://www.assistfund.org)) provides financial support to chronically ill patients with high-cost medications.

**The Patient Advocate Foundation** (800-532-5274 or [www.patientadvocate.org](http://www.patientadvocate.org)) provides education, legal counseling, and referrals for people with cancer who need assistance managing insurance, financial, debt crisis, and job-discrimination issues.

**The Carbone Cancer Center is going to do something different this year for their annual fundraising run.**

Participants can designate specifically where their fee and/or donations go, so that you can directly support Myeloma research. The run is 5K or there is a 1K walk. The website for the event is [www.uwhealth.org/race](http://www.uwhealth.org/race). This could be a joint effort of our group to participate in this run/walk event. Something to think about....

**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. Debbie, 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”.  
Send to: Maureen Dembski, Director of Development  
UW Carbone Cancer Center  
University of Wisconsin Foundation  
1848 University Avenue  
Madison, WI 53726  
[maureen.dembski@supportuw.org](mailto:maureen.dembski@supportuw.org)