



“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 January 20, 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@themmrf.org">info@themmrf.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. Aric Hall (oncology fellow, third year) has agreed to do a Q&A on Feb. 17th from 4:30 to 5:30.

Debbie Boldt-Houle, Senior Director Scientific Affairs from the Binding Site, Inc has agreed to speak at the April 21<sup>st</sup> meeting. She will present information about the Freelite testing.

A big thank you to Mary Lou and Larry Hudack, Darlene and Tony Nowak and Nona Suhr for their generous donations to our support group. Those contributions will go towards the newsletter expenses and printer costs. It is very much appreciated.

### **Curetalks or [curetalks.com](http://curetalks.com)**

Someone mentioned this new site at our last support group meeting. I had a chance to listen to Dr Parameswaran Hari talk about the ASH 2014 Myeloma updates. He spoke about 1<sup>st</sup> time induction therapies and how they are discovering that 3 drug combos are more effective than 4 drug combos. Studies are still ongoing to put a 4 drug combo together with drugs that complement each other and not impact the effectiveness of each other. The thought behind pursuing the 4 drug combo is to hit the myeloma hard to get better outcomes.

He spoke about new Relapse or Refractory drugs- Kypolis and Pomalyst. Clinical trials revealed that the single agent drugs were less effective than drug combos much like the 1<sup>st</sup> time induction results. Also targeted antibody drugs are being studied with great results. Currently Revlimid/Dex combo produces 17 months to progression while Revlimid/Dex and Kypolis yields about 26 months to progression. Results can be read in the ASPIRE study just published. Here again, 3 drug combos are showing better results than single agents or 2 drug combos.

He also spoke about how Myeloma is being redefined. Smoldering high risk patients are now being treated earlier due to this new evaluation of disease. Clearly there is a benefit to these new patients to do so.

## **Additional Resources** (*Note - Many libraries provide free internet access*)

**BMT InfoNet (Blood & Marrow Transplant Information Network)** Website: [www.bmtinfonet.org](http://www.bmtinfonet.org), email: [help@bmtinfonet.org](mailto:help@bmtinfonet.org), phone: 888-597-7674. BMT InfoNet is a not-for-profit organization dedicated to serving the needs of persons facing a bone marrow, blood stem cell or umbilical cord blood transplant.

**CancerCare** is a nonprofit organization that helps people with cancer, their families and professional caregivers. CancerCare provides several free teleconferences each year on multiple myeloma and other cancer care issues. Call 1-800-813-HOPE or check their website at [www.cancercare.org](http://www.cancercare.org) for additional information.

**CaringBridge**: CaringBridge provides free websites that connect family and friends during serious health events, care and recovery. A CaringBridge website is personal, private and available 24/7. It helps ease the burden of keeping family and friends informed. Authors add health updates and photos to share their story while visitors leave messages of love and support in the guestbook. Visit [www.CaringBridge.org](http://www.CaringBridge.org) for more information.

**The Center for Patient Partnerships**: A University-based cooperative, interdisciplinary project that works to assist patients and families who are experiencing red tape. Call 608-265-6267, email [cpp@law.wisc.edu](mailto:cpp@law.wisc.edu), or check the website- [www.lawwisc.edu/patientadvocacy](http://www.lawwisc.edu/patientadvocacy).

**The Chronic Disease Fund** Website: [www.cdfund.org](http://www.cdfund.org) Provides financial assistance to under-insured patients who are diagnosed with chronic or life altering diseases that require the use of expensive, specialty therapeutics. Multiple Myeloma is among the diseases covered by the Chronic Disease Fund.

**The Cleveland Clinic Multiple Myeloma Research Center**: [www.clevelandclinic.org/myeloma/](http://www.clevelandclinic.org/myeloma/)

**CURE** magazine provides cancer updates, research and education information quarterly. **CURE** has an impressive editorial board of medical professionals. Published by The Cancer Information Group, LP, subscriptions are free by calling 1-800-272-4909. For more information or back issues, visit [www.curetoday.com](http://www.curetoday.com)

**FDA – Center for Drug Evaluation and Research**: <http://www.fda.gov/cder/drug/default.htm>

**Healthtalk**, dedicated to providing the latest information by trusted experts: <http://www.healthtalk.com>

**Myeloma Institute for Research and Therapy**, Arkansas. <http://myeloma.uams.edu/index.htm>

**The Mayo Clinic**: <http://www.mayoclinic.org/multiplemyeloma-rst/index.html>

**Medifocus**. [www.medifocus.com](http://www.medifocus.com). Since 1996, Medifocus has been a leading provider of health information for patients and families confronting serious medical issues.

**Memorial Sloan-Kettering Cancer Center**: <http://www.mskcc.org/mskcc/html/3371.cfm>

**The Myeloma Beacon**: <http://www.myelomabeacon.com/> Up-to-date news & information for Myeloma patients.

**Myeloma Today** is a free newsletter published six times each year by the International Myeloma Foundation (IMF). Call 1-800-452-CURE (2873) to be added to the mailing list or subscribe on the IMF website.

**Myeloma Minute** is a weekly update of myeloma information produced by the IMF. The Myeloma Minute provides information on clinical trials, events, research titles, research reviews and much more.

**Myeloma Focus** is a free quarterly publication of the Multiple Myeloma Research Foundation (MMRF). Call the MMRF at 203-972-1250 or subscribe at their website.

**SmartBrief**, a weekly email sponsored by the MMRF, provides timely updates on items related to multiple myeloma including treatments, clinical trials, latest research information, and much more. Access SmartBrief at the MMRF website.

**National Cancer Institute**, U.S. National Institute of Health: [www.cancer.gov](http://www.cancer.gov)

**National Family Caregivers Association**: Dedicated to serving all family caregivers regardless of their relationship to the person receiving care or that person's medical condition or diagnosis. For information call 800-896-3650 or check the website- [www.nfcacares.org](http://www.nfcacares.org).

**The Neuropathy Association**. <http://www.neuropathy.org> For more information call 1-800-247-6968.

**Patient Advocate Foundation**. "Insuring equal access to healthcare for all Americans". Assistance with any health/insurance-related issues. Online: [www.patientadvocate.org](http://www.patientadvocate.org) or 1-800-532-5274.

**People Living with Cancer**, a patient information site of ASCO: <http://www.plwc.org>, <http://www.cancer.net>

**Q1Medicare.com** is a website dedicated to providing up to date Medicare Part D information (not maintained by the government).

**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)