



“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 August 16, 2016 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
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More Information:

International Myeloma Foundation (IMF)	Multiple Myeloma Research Foundation (MMRF)
Phone: 800 - 452 - 2873	203 - 972 - 1250
Email: TheIMF@myeloma.org	info@themmrf.org
Website: www.myeloma.org	www.multiplemyeloma.org

Upcoming speakers

- **October meeting- Dr Natalie Callander** will be speaking from 4:30pm-5:30pm
- **Dr Kevin Kozak, Chief Medical Officer, Cellectar Biosciences** will be speaking to our group about the historical evolution of the role of radiation therapy in the management of myeloma. That meeting date is to be determined yet. Possible dates would be November 2016 or January 2017. More info to follow.

Our Condolences to the Fuerstenberg family

Our group member, Bob Fuerstenberg passed away July 26, 2016. He and Susanna joined our group August 2014. They attended many meetings and freely asked lots of questions in an effort to learn as much as they could to make good decisions about Bob's treatment. He participated in trying many of the newer treatments but was not able to manage a long term remission. Our deepest sympathies to his family.

Thank you to Corrie and Ron Nagl for their generous donation to the group. It will be used for printing and postage of our newsletters. It is always nice to get a personal note from those folks who live farther away and are not able to make as many meetings as they would like to. Love the notes!

Peggy Wellman from Takeda was our meeting speaker for the July session.

Peggy mentioned a new website that is very simple to use “chemocare.com”. It has easy to read **Drug Info** and **Managing Side Effects** sections. This website is worth checking out! Peggy recommended to reread your current medicine information guides. Especially if you have been on a medication for some time now, you may have forgotten about some possible side effects that may be bothering you right now. It may be the answer to some nagging questions about why you don't feel so well.

On the IMF website under IMFTV.... Ask Dr Durie

He speaks to the question – “What should be done to carefully monitor Myeloma in the remission phase?” This question was asked by a patient and Dr Durie addresses this subject in a 5 minute presentation. www.myeloma.org

Found this quote that was worth sharing..... **The Power of Presence**

Reflection of the Day: *"The most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention... A loving silence often has far more power to heal and to connect than the most well-intentioned words."* -Rachel Naomi Remen, author

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 info@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".

Katie Williquette

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

- **BMT InfoNet (Blood & Marrow Transplant Information Network)** Website: www.bmtinfonet.org, email: 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 for additional information.
- **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 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, or check the website- www.lawwisc.edu/patientadvocacy.
- **Good Days from CDF** Website: 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/
- **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
- **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. A leading provider of information for patients 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 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 at www.multiplemyeloma.org.
- **SmartBrief**, a weekly MMRF email, 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
- **National Family Caregivers Association:** Dedicated to caregivers regardless of their relationship to the person receiving care or that person's medical condition or diagnosis. Call 800-896-3650 or go to www.nfcares.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 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).