



“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 18, 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.

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More Information:

International Myeloma Foundation (IMF)	Multiple Myeloma Research Foundation (MMRF)
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Email: TheIMF@myeloma.org	info@themmrf.org
Website: www.myeloma.org	www.multiplemyeloma.org

Upcoming speakers

- Tentative plans for Dr Natalie Callander to speak at the October meeting.
- 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.

Our August meeting speaker will be Dr Lori DuBenske, PhD UW Psychology.

Mark your calendars now not to miss this meeting! Dr DuBenske will join us from 3:30pm-4:30pm.

Just a quick thank you to our special guest, Dr Susan Dunnett from the University of Edinburgh Business School in Scotland. Susan was in Madison during July and attended our meeting. Nine years ago, Susan was in the United States for 18 weeks to complete her thesis. Her work entitled “The Transformed Consumer: collective practices and identity work in an emotional community” was in part her interviews with some of our support groups members. I had the privilege to read it (267 pages) and was “transformed” in my definition of our group. If you have any reservation about support groups, consider this.... We are a community of individuals that are intelligent about this disease. We are a community of savvy consumers in that we want to understand and secure the best treatment for ourselves. We are a community of caring, honest and energetic people willing to share and comfort. Susan used the following quote “If there is to be a community in the world of individuals, it can only be (and needs to be) a community woven together from sharing and mutual care; a community of concern and responsibility for the equal right to be human and the equal ability to act on that right.” (Bauman 2001:149-150) So, we are a community in every sense of the word. So much more than a support group. Ponder that!

Freelite recap

Debbie Boldt-Houle, Senior Director Scientific Affairs from the Binding Site, Inc. spoke at our July meeting. What we learned... Antibodies fight bacteria, neutralize viruses and poisons and help other cells kill infected cells. Antibodies are proteins made up of heavy chains and light chains. When bad plasma cells make antibodies, extra

light chains or “free light chains” are made. These plasma cells also produce Immunoglobulins (M-protein). There are two types of Free Light Chains-Kappa and Lambda. The highly sensitive Freelite test helps discover these chains long before the standard testing methods: Protein Electrophoresis in serum or urine (SPE, UPE), Immunofixation (IFE) or Total immunoglobulins (eg. IgA). Watch for differences in testing labs and hospitals. Watch for Milligram/liter ↔ Gram/deciliter Conversion differences. The difference is significant. See below:

$$1 \text{ mg/L} = 0.0001 \text{ g/dL}; 1 \text{ g/dL} = 10000 \text{ mg/L}$$

In summary, the Freelite test lets you know if your current new treatment is working much sooner than the standard testing methods. If this test is not currently available to you, speak up and find out why not. It is important to know why not. You will want to advocate for it to be part of your routine.

Save the date!

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!

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.

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

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