



“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 May 19, 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:**

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### **Upcoming speakers**

- Debbie Boldt-Houle, Senior Director Scientific Affairs from the Binding Site, Inc. will join us in July. She will present information about the Freelite testing.
- 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 condolences to the family of Mike Morgan.**

Mike joined our group October 2002. He received our newsletters but did not attend regular meetings. Mike was a dedicated IT worker and committed to his job at American Family Insurance. Mike had an allogenic transplant and struggled with Graft vs. Host disease as well as his Myeloma. He was a 13 year survivor. We extend our sympathy to his family.

**An important reminder... Effective January 1, 2015, the “Cancer Treatment Fairness Act” (SB300) makes oral chemo therapy drug co-pays limited to a maximum \$100.** Request your reimbursement if you get over-charged. This information applies to Wisconsin residents. Check for your state on the IMF advocacy site.

### **NBC Dateline May 7<sup>th</sup> - Tom Brokaw shares his journey with Multiple Myeloma.**

This NBC Dateline program can be seen in its entirety if you have “On Demand” cable service. You can also view it at [www.npr.org](http://www.npr.org). Once on the NPR site, search for “Tom Brokaw”. Tom shares his personal journey and includes interviews with his family. This hour long program was compelling and very informative. It is worth watching!

## **Great resource for new folks! "Glossary of Myeloma Terms & Definitions" and "Guide to Myeloma Acronyms and Abbreviations"**

Group member Mary passed along this helpful information. With so many new members, this guide is a great tool to keep all the terminology straight. The IMF has updated both sources. It is available on their website. [myeloma.org](http://myeloma.org) -> Choose the tab "about myeloma" -> "newly diagnosed" -> "Learn the Vocabulary". You will find both the "Glossary of Myeloma Terms & Definitions" and "Guide to Myeloma Acronyms and Abbreviations". As with earlier versions, it can be printed or saved as text or pdf. For the new members, if you are confused by the terms... take it to your next clinic appointment.

**Another great resource for new folks!** "Lab Tests Online" website is my go to place for information about the many lab tests ordered by your doctor and/or hospital. Check it out! [www.labtestsonline.org](http://www.labtestsonline.org)

Do you have a resource that you would like to share? Email me at [schwartzdon@sbcglobal.net](mailto:schwartzdon@sbcglobal.net). I'll check it out and possibly highlight it in an upcoming newsletter.

## **CancerCare Online Support Group for Multiple Myeloma starts June 1<sup>st</sup>.**

This 15-week online support group is for people diagnosed with multiple myeloma who are currently receiving treatment. This group led by an oncology social worker will give patients support to each other and share resources/ information. **To join this group, you will need to complete the online registration process. After joining this password-protected group, you can read and post messages 24 hours a day, 7 days a week. Start Date- Monday, June 1, 2015 (Group accepts new members after start date.) End Date- Tuesday, September 15, 2015 Register [Begin registration process now.](#)**

Blog post by Dr. Brian GM Durie on Thu, 04/16/2015 - 12:30



As we continue to fight for the development of and access to new and better drugs, increasing numbers of myeloma patients are already living longer—certainly beyond 5 years, and often beyond 10 to 15 years. That's certainly great news! But long-living myeloma patients need specialized care plans. Here's a checklist to help those patients stay alert to red flags which call for special attention:

A key first step for patients is to **review any ongoing maintenance and/or supportive care measures**: Is maintenance needed and/or helping? Are there any downsides? Has there been any impact on blood counts, neuropathy or bones? An initial option is dose reductions, if needed.

**Watch for progressive reductions in white blood cell counts, hemoglobin (anemia) and/or platelets**, which can lead to problems. Reduced levels of neutrophils (white blood cells) are a particular concern because of increased susceptibility to infections. This deserves discussion with your doctor, especially if infections have become a problem or if there have been episodes of fever, or if low-level/opportunistic infection is suspected.

**Hidden infection in sinuses, teeth, kidney or bladder areas** can go unnoticed. Don't hesitate to have any recommended evaluation or testing. Blood testing can show antibody levels to things like Lyme disease or toxoplasmosis (a parasite infection). PET/CT scanning can reveal small areas of infection in sinuses or soft tissue areas, which may require attention.

**Ongoing use of steroids**, such as dexamethasone, can be helpful but harmful with long-term use. I strongly recommend a frank discussion with your doctor about when to stop steroids.

**Blood-sugar levels** can increase and then turn into full-blown diabetes. **Cataracts** can develop requiring surgery. **Loss of elasticity in skin** and soft tissues leads to easy bruising. There is also increased risk of infection.

A rare but sometimes serious problem is **hip damage** called AVN (avascular necrosis of the head of the hip bone), which can lead to arthritis, pain and limitation of movement. Replacement surgery can be required. These and other potential problems are sufficiently important to require detailed discussions with your doctor. Are steroids still required? Can the dosage or frequency be reduced? Can they ultimately be stopped? Well-known issues for myeloma patients include development or progression of **neuropathy**, requiring dose reductions or discontinuation of Velcade or any other triggering drug. **Use of bisphosphonates** should not be open ended. Both Aredia and Zometa can lead to longer-term problems, including osteonecrosis of the jaw (ONJ) or even atypical fracture of the femur (upper leg bone). Therefore, reducing the frequency and/or duration of bisphosphonates is recommended.

### **Important Patient-Doctor Discussions**

Beyond all this is the good news that you are living longer. However, always be alert to possible health issues that can affect us as we age—whether myeloma patient or not. Heart or lung disease, hormone or metabolic problems, even a second cancer can sometimes occur. To stay ahead of potential problems, I strongly recommend **regular monitoring and follow up by an internist or general practitioner**, as well as any specialists whom you may have seen in the past.

What should you be looking for to stay healthy? Watch for diabetes, high blood pressure, heart disease, low hormone or vitamin levels (thyroid hormone vitamins D or B12 for example) or early second cancer. All of these are possible—but, thankfully, unlikely, except low vitamin D levels, which are actually quite common and should be treated with daily supplements.

**Normal monitoring** is recommended, including colonoscopy. I particularly recommend **whole body PET/CT** (approximately annually if feasible) for monitoring. This is an excellent way to monitor low-level myeloma and can also detect hidden infection or an early second cancer. My personal experience is that colon or breast cancer detected early can be dealt with in a curative fashion.

So, I've given you a lot to think about. Although this is not a comprehensive list, it is hopefully sufficient to set you on the right path. Take time to discuss ongoing therapies with your doctor and strongly consider working with an internist to monitor your general health.

With longer remissions you want to be in the best shape for the longer term, and incorporate the best diet and exercise programs.

### **Get Help with Co-Pays**

Do you or someone you love need help paying co-payments for chemotherapy and cancer medications? The **CancerCare® Co-Payment Assistance Foundation (CCAF)** is dedicated to helping people afford their co-payments for chemotherapy and targeted treatment medications.

We currently have funds available for these diagnoses:

- Metastatic breast cancer
- Non-small cell lung cancer (NSCLC)
- Colorectal cancer
- Pancreatic cancer
- Glioblastoma
- Gastric cancer
- Multiple myeloma

[Visit our website](#) or call **866-55-COPAY** (866-552-6729) to learn more or to enroll.

**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 [info@myeloma.org](mailto: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”.

Send to: Maureen Dembski, Director of Development

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