



“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 July 15, 2014 3:30 – 5:30 PM**  
**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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3309 Chicago Avenue  
Madison, WI 53714-1815

**More Information:**

International Myeloma Foundation (IMF)	Multiple Myeloma Research Foundation (MMRF)
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Website: <a href="http://www.myeloma.org">www.myeloma.org</a>	<a href="http://www.multiplemyeloma.org">www.multiplemyeloma.org</a>

**Upcoming Speakers...save the dates!**

For the August meeting, Carrie Bilicki- Oncology nursing Froedtert Hospital, Milwaukee, WI. Topic- “Caring for the Caregiver”.

**Our condolences...**

It is with great sadness that I report the passing of our group member, Karen Stevenson. Karen passed away Wednesday, June 25, 2014. She and her husband, Bernie Cesnik joined our group March 2011. They attended several meetings and were eager to share what they knew. We will miss her smile, laughter and good nature. Our sympathy to Bernie and family.

**June’s meeting speaker was from SHIP (State Health Insurance Program), Jill Helgeson, Medigap Counselor.** The program was entitled “Fitting the Pieces around Medicare”. What I learned was that the sheer scope of all the coverage and its requirements is daunting. There are many pieces to this puzzle and asking for help is the smartest strategy. Jill brought many brochures and made it clear that calling and reviewing this material is welcomed by her staff. If you are not well enough to make the calls, I am sure that Jill will work with your designated person with permission.

**[Found this interesting article... thought you techy people might like it.](#)**

**Chemo Brain Doc Notes App**

When Jenny Ahlstrom wanted to discuss her multiple myeloma with her oncologist, she would often “go in with mental questions and leave with nothing answered.” So, she created **Chemo Brain Doc Notes**, a free app for

iPhone and Android devices that helps patients and caregivers remember important questions, record discussions with their doctors, retain complex medical terminology and create reminders about prescriptions, side effects, symptoms and test results.

“As a patient, I understand the complexities and challenges of going through chemo and the effects it can have,” Ahlstrom says. “I think this is a simple, easy solution.”

In addition to easily creating and organizing text notes into folders by topic, the app enables users to add voice memos with playback. A one-time \$1.99 in-app purchase allows users to email recorded memos, “So the whole family can be on the same page when it comes to treatment,” Ahlstrom says. All proceeds from the app go to fund patient support, education and cancer research. Search for Chemo Brain Doc Notes in the [App Store](#) or on [Google Play](#). BY JON GARINN  
PUBLISHED JUNE 15, 2014 in the CURE Magazine

Also in the June CURE magazine on pg. 46, “**Lessons Learned when trying to cope with Peripheral Neuropathy**”.

This article is very good at detailing Peripheral Neuropathy and the current treatment methods. It speaks to the Scrambler project and other interesting ideas. You can google CURE magazine and then the title above to read it. Article was too long to include it in this newsletter.

### **Attention Relapsed/Refractory Myeloma Patients**

If you are a myeloma patient with Relapsed (your disease has progressed) and/or Refractory (you have not responded to initial therapy or have relapsed within six months of initial therapy) disease, and your disease has progressed despite treatment with new therapies like Revlimid and Velcade, there are clinical trials with new treatment options available to you.

By calling **866-603-6628 (MMCT)**, a trained clinical trials specialist will help you to complete a personalized profile to find trials that are right for you. The service is free and all submitted information is kept strictly confidential. Alternatively, log on to [www.MyelomaTrials.org](http://www.MyelomaTrials.org), and complete the profile yourself.

It is important for you to know that you do have options even if you are no longer responding to the latest therapies. And, the more people who participate in clinical trials, the faster critical research questions can be answered that will lead to better treatment options for all patients.

**Multiple Myeloma Research Foundation** 383 Main Avenue, 5th Floor Norwalk, CT 06850

### **Trillium Research update coming soon**

I contacted Maureen Dembski about a Trillium research update. She was willing to begin planning a presentation. More info to follow. This is a presentation that has always been very interesting and hopeful.

### **Save the dates...**

Upcoming **IMF Patient and Family Seminars**-

August 22-23 Los Angeles, CA

October 10-11 Short Hills, NJ

The website to access information for these 2014 Seminars is:

<http://myeloma.org/EventIndexPage.action?tabId=7&menuId=111&queryPageId=4&parentTabId=7&parentMenuItemId=111&parentLinkId=0&parentNuggetId=0>

LLS 12th Annual Multiple Myeloma Survivorship Conference

Featuring LLS Board of Trustees Chairperson, Man of the Year- patient advocate/myeloma survivor Paul Westrick

When: Saturday, September 13, 2014

Where: Country Springs Hotel, 2810 Golf Road, Pewaukee, WI 53072

Time: 9:00 a.m. to 3:30 p.m. See attachment

MMRF Educational Event

**Program Topics:**

Myeloma 101: Prognosis and Risk

Treatment Options for Newly Diagnosed Patients

Stem Cell Transplant

Treating Relapsed/Refractory Disease

Supportive Care Options

Promising Clinical Trials

Faculty Q & A

Twin Cities, MN September 27<sup>th</sup> Register today at [www.themmr.org/clinicalinsights](http://www.themmr.org/clinicalinsights)

**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.

**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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University of Wisconsin Foundation

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