

"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 19, 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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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: TheIMF@myeloma.org info@themmrf.org

Website: www.myeloma.org www.multiplemyeloma.org

Upcoming event!

Working with the Trillium group for a presentation of their work at the Wisconsin Institutes for Medical Research (WIMR). This presentation will likely be in October. Keep October dates open and don't miss this special event. More info to follow.

<u>August meeting speaker.... Carrie Bilicki,</u> Oncology nurse from Froedtert Hospital Milwaukee, WI. Topic- Caring for the Caregiver.

I have asked Carrie to present her information to the group and allow us to separate into two groups-patient and caregivers for discussion. She will be available to answer questions and facilitate discussion between both groups as needed. Our subject interests were submitted to her early.

Emergency Medical summary

As part of our discussion at our last meeting, Mary Levin introduced the concept of always having an "Emergency Medical summary". When a crisis sends you to the ER or a clinic far from home, this summary is extremely valuable. Getting concise information to those medical providers is critical to save time and reduce anxiety for all parties. You can streamline all the questioning that those providers have to do to get a full picture of your loved ones medical history and struggles. It can be very frustrating to answer general questions from multiple people before any treatment occurs. This summary shortens that time and effort. Remember Doctors may be looking for "Horses not Zebras". Having Myeloma is more like Zebras. Help your providers give you the best care possible. The summary is attached and can be modified/edited to fit your situation. If you think of something that I should add for the benefit of all, send me a note.

More on the Measles vaccine ...

Balveen Kaur of Ohio State University says scientists want to train viruses to be like James Bond, and give them a license to kill...cancer, that is. She and other research groups are working to make herpes, measles, and other viruses capable of targeting and destroying cancer cells. Kaur and Stephen Russell of the Mayo Clinic discuss advances in the field of cancer-killing viruses and how to move these treatments from the lab to the clinic.

This was on National Public Radio (NPR), Science Friday. More information on MM and the treatment with measles vaccine. Link: http://sciencefriday.com/segment/08/08/2014/giving-viruses-a-license-to-kill-cancer.html
It was about 7 or 8 minutes long and very informative.

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

Living Successfully with MULTIPLE MYELOMA

IMF Regional Community Workshop

Saturday, September 6, 2014

The Westin Chicago North Shore 601 N. Milwaukee Avenue, Wheeling, IL

Registration: 9AM! Workshop 10AM - 3PM

To register: 800-452-CURE (2873) - Ask for Regional Community Workshop registration

<u>Understanding the Immune System and Lab Values in Myeloma -</u> Living Well with Myeloma Teleconference Series http://labvalues.myeloma.org 1.800.452.CURE (2873)

Date: Thursday, August 28, 2014

Time: 4:00 p.m. Pacific / 5:00 p.m. Mountain / 6:00 p.m. Central / 7:00 p.m. Eastern

Duration: 60 minutes including Q&A

Speaker: Ann McNeill, RN, MSN, APN-C (and member of the IMF's Nurse Leadership Board)

Multiple Myeloma Division The John Theurer Cancer Center Hackensack University Medical Center

Hackensack, New Jersey

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 27th Register today at <u>www.themmrf.org/clinicalinsights</u>

<u>IMF Info Line</u> – 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 <u>infoline@myeloma.org</u>.

<u>The **Trillium Fund**</u> 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