



“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 December 16, 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.

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More Information:

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

The Trillium presentation was a huge success! More than 70 people signed up to attend. Dr Natalie Callander gave an update on the Myeloma Clinical Research program. Dr Peiman Hematti, spoke briefly about the challenge of keeping Myeloma cells alive outside the body long enough to work with them in the labs. Myeloma cells die very quickly outside of the body making any research difficult. Dr Catherine Leith talked about her work with the bone marrow biopsies that are collected from patients at the Carbone Cancer clinics. She remarked how she may never have met you in person but she knows your name and your biopsy. Dr Erin Costanzo noted the impacts of behavioral influences following stem cell transplants. Her work affirms the link between having positive outcomes when a positive mind set is also present. One of the more interesting presentations was from Dr. Jeff Jensen-”How to Turn the Immune System against Myeloma”. His work revolves around learning how to make cells take action against Myeloma.

I hope all who attended walked away with a better understanding of what type of research and work is being performed by the Myeloma Clinical Research program. This program is supported by the Trillium Fund. Information on how to contribute is at the end of this newsletter.

A very generous contribution of \$10,000 was presented to Dr Natalie Callander and Dr Fotis Asimakopoulos on behalf of a group member who could not attend the presentation in person. My personal thank you to all who participated; whether you were there in person or in spirit.

This may be something that you could share with your oncology team.

A new Myeloma education series for health care professionals has been created by the Leukemia & Lymphoma Society (LLS). It is called **“Myeloma Rounds”**.

The continuing medical education program was the first in the Leukemia & Lymphoma Society's (LLS) new **“Myeloma Rounds”** series focusing on advances in the management of patients with myeloma. LLS developed the program as a way to help physicians and other health care professionals build their disease knowledge and encourage collaboration with their colleagues.

Additional Myeloma Rounds presentations will be scheduled, including a second Philadelphia program in the spring. Posted by [lynnsmith](#), in [Myeloma Blog](#) 14 November 2014

Are you looking for a second opinion?

This subject came up at our last group meeting. I asked the nurse coordinators at the UW Carbone Cancer center for help on this subject. Soon, I had three nurses sharing their working knowledge of how best to get this done. Here is what they recommend. First and foremost, check with your insurance company. If Medicare has denied coverage, don't give up. Find out how you can appeal their denial. If there are going to be out-of-pocket costs, negotiate with the facility.

Start with your current oncologist and let them know that you would like to seek out a second opinion. Your doctor should be willing to help you put together everything that you need to do this. If they are not willing to help you, this may be a sign you are seeing the wrong provider. You will need to know who you want to go see. A second opinion should be outside of your current clinic. The IMF and the NIH both have the names and addresses of many Myeloma experts around the country. Let your current doctor know who you will be seeing. Find out what test results will be needed for your second opinion visit. Be aware that you may be asked to undergo some additional testing.

Be prepared with your questions. Don't be afraid to bring along a family member or friend to help you get all your questions answered. It is not unusual to want a second opinion if your Myeloma returns later.

Is shopping on your To-Do list?

Did you know that you can shop with the leading merchants on the internet and receive the same price as anyone else visiting their sites, and support the IMF at the same time? A percentage of your purchase goes to support the IMF, not from your purchase price, but from the vendor.

Remember, **USE THE LINKS AT SHOP.MYELOMA.ORG**. You may want to bookmark this page to ensure that when you are shopping your purchases are properly credited. And keep checking back as the IMF adds new stores to our Mall.

For anyone who shops Amazon.com, a 6% commission on all purchases goes the International Myeloma Foundation (IMF). To do this use the link, <http://amazon.myeloma.org> (not the standard <http://amazon.com>). This will take you to the same site, but the IMF gets that 6% credit, thus helping all of us toward that cure we need. Also, please consider asking your family and friends to also use the <http://amazon.myeloma.org> link.

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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