



“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 April 19, 2016 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.

Information: Jayne Schwartz 608- 244-2120
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Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue
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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 speakers

- **May meeting-** Tentative speaker, Dr Michael Huie, Oncologist Carbone Cancer Center
- **June meeting-** Dr Aric Hall, UW Hematology faculty member will do a Q&A starting at 4:30pm
- **July meeting-** Peggy Wellman from Takeda will be returning. Topic to be determined later.

Our Condolences

It is with great sadness that I share news of the passing of Tim Laatch. Tim joined our group May 2003. He was a generous, kind and supporting member of our group. Tim had a stem cell transplant 14 years ago at Easter time. He experienced many of the early treatment protocols and was a great resource for others. He will be missed but not forgotten. He was a comfort to all new members and supported the group's discussions with humor and honesty. Our sympathies to his wife, Jaci and his family.

Thank you Al for your generous contribution to the group! It is appreciated.

April meeting speaker- Jill Helgeson from SHIP-(State Health Insurance Program). Jill was our meeting speaker June 2014. At that time, she was a Medigap Counselor. Her 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 made it clear that calling and reviewing your questions 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. Mark your calendars now and don't miss this informational meeting from our SHIP representative. You will enjoy her presentation.

The IMF is hosting a webinar titled, "NIH Funding: How it Benefits You as Patient" on April 13, 2016 at 7:00 EST! This webinar will focus on the importance of advocating for research funding at the National Institutes of Health (NIH), specifically how certain programs, such as grants for young, emerging researchers and funding for clinical trials, impact myeloma patients. We will have corresponding engagements available so patients can

contact their legislators and ask them to support NIH funding. Patients can register here: <http://cqrcengage.com/myeloma/NIHwebinar>



Information from the IMF Advocacy group...

The multiple myeloma community received good news last month when the Center for Medicare and Medicaid Services (CMS) announced they were modifying their National Coverage Determination for allogeneic stem cell transplants. The new determination states that allogeneic stem cell transplants will be covered by Medicare for patients with stage II or III myeloma and who are participating in a clinical trial.

The trials must be focused on studying the comparative effectiveness of treatments, with a specific focus on looking at outcomes related to host vs. graft, other transplant related adverse events, overall survival and quality of life. Previously, CMS did not cover allogeneic transplants under any circumstances. To read the National Coverage Determination, [click here](#). And if you have any questions, please email advocacy@myeloma.org.

IMF new booklets! We have new publications about Ninlaro (ixazomib) capsules, Emluciti (elotuzumab) and Kyprolis (carfilzomid). These are the 3 newest drugs approved for Myeloma treatment. There is also a new booklet entitled, Understanding Your Test Results. It is small enough to bring to your clinic appointments. Something else you should be bringing to your clinic appointments is the IMF's booklet entitled – Concise Review of the Disease and Treatment Options. This one should be distributed to every clinic nurse and doctor that treats your Myeloma.

Ever been in the doctor's office and run into a person that has Myeloma? Know a friend who has a friend with Myeloma? Ever wish you had the email address, phone number of your support group? I had 500 business cards made up with just that information. You can request that I send you some but promise me that you will put them in your wallet/purse and use them to help others find a group. Even if you are not attending a meeting in person, I would be happy to include anyone on the email list. We currently have almost 200 emailers that are from England, Norway to Alaska. One more is welcome!

Save the date....

April 14, 2016 Cancercare presentation on the "Progress in the Treatment of Multiple Myeloma. Sign up on the Cancercare website.

April 28, 2016 Cancercare presentation on "Coping with the Stress of Caregiving When Your Loved One has Multiple Myeloma". Sign up on the Cancercare website.

April 30-May 1, 2016 "Celebrating a Second Chance at Life", a symposium for bone marrow, stem cell and cord blood transplant survivors. Register now at www.bmtinfonet.org/Chicago2016 or phone 888-597-7674

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.

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".

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