



“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 October 20, 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.

Information: Jayne Schwartz 608- 244-2120
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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@themmr.org
Website: www.myeloma.org	www.multiplemyeloma.org

Upcoming speakers

- 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.
- December meeting speaker will be Peggy Wellmann, Clinical Nurse Educator Takeda Oncology. Peggy will present “Understanding Lab Values”.
- January meeting- Sue Enright from the IMF will speak to the group. Weather permitting.

Dr Natalie Callander will be our speaker at the October meeting. She will present at 4:30pm. Mark your calendars now!

Coming soon.... Our own website! Group member, Allen is currently creating our website. You will be able to find copies of the newsletters, information on many subjects and announcements that you will be interested in. More information coming soon.

LLS Myeloma Conference from September 12, 2015

Karen Ropel is gathering speaker information and slides that will be available to anyone who would like to review the breakout sessions and conference presentations. This information will be on the LLS website for access. She promised to email me with the details as she completes her work.

For Wisconsin residents.... State Health Insurance and Assistance Program or “SHIP”

Assistance finding the best Medigap and Part D insurance for your unique needs. Also able to provide info on how to qualify for drug assistance programs. **No cost to you. Your taxes fund this program.**

Part D & RX Helpline (over age 60) 1-855-677-2783

Part D & Disability Drug Benefit Helpline: 7-800-926-4862

Medigap Helpline: 1-800-242-1060

Contact Tracy Lipinski, Medigap Insurance Counselor 608-246-7006 or 1-800-242-1060

Tracy.Lipinski@Wisconsin.gov

Vicki Buckholz, Supervisor 608-246-7016

At the June 2014 group meeting, our speaker was Jill Helgeson, Medigap Counselor from SHIP (State Health Insurance Program). We continue to benefit from her presentation. This service is very helpful and does not try to sell you anything.

Cancer Crowdsourcing Initiative Winners Selected

SALT LAKE CITY, Aug. 19, 2015 /PRNewswire-US Newswire/ -- The Myeloma Crowd Research Initiative (MCRI), an unprecedented collaboration of cancer researchers and patient advocates, today announced the two winners of its first-ever crowdsourcing and patient-led initiative to fund research in high-risk multiple myeloma, a rare malignancy of plasma cells. MCRI has pledged up to \$500,000 over two years for both grants combined.

"High-risk myeloma should be one of the top priorities for myeloma researchers," said Dr. Rafael Fonseca of the Mayo Clinic Scottsdale and a member of the MCRI panel. "New and radically different treatment approaches are needed."

The recipients are a team of researchers at the University of Wurzburg, Germany and the Johns Hopkins Sidney Kimmel Comprehensive Cancer Center in Baltimore, who will study two different ways of modifying immune system cells in the blood and bone marrow to develop personalized immunotherapies for myeloma patients with the worst prognoses.

Research by Drs. Hermann Einsele and Michael Hudecek in Wurzburg will genetically engineer receptors on a type of white blood cells, called CAR T-Cells, to attack two specific targets found on myeloma cells and not found on normal cells. The therapy developed would be a one-time treatment and not used with transplant or other combination therapies.

"CAR therapy is at the same time cell therapy, gene therapy, and immunotherapy," according to Dr. Michael Sadelain of Memorial Sloan Kettering Cancer Center. "It represents a radical departure from all forms of medicine in existence until now."

The second recipient is Dr. Ivan Borrello of Johns Hopkins who is working on enhancing white blood cells to create a patient-specific immunotherapy. Using the patients' own bone marrow, he expands the immune fighting cells a hundredfold in the presence of the tumor cells and then gives them back to the patient after stem cell transplant. When given back to the patient, the "training" helps to T-Cells go after hundreds of tumor-specific signatures and takes advantage of the body's natural immune cell regrowth post-transplant.

"Current treatments are generally used to extend survival curves but typically don't access the possible benefits of our own immune system," said 20 year myeloma survivor Jack Aiello, a member of the MCRI selection team. "I'm excited about these two proposals providing myeloma patients with even better treatment options than we have today."

"MCRI is a unique collaboration between passionate and highly educated patients, a world class scientific advisory board and the brightest researchers from around the world to find and accelerate innovative treatments for high-risk myeloma patients," said Jenny Ahlstrom, President of the CrowdCare Foundation. "The MCRI initiative is the first focused effort to address the needs of high-risk patients who, today, have especially poor outcomes."

Multiple myeloma is a cancer of the plasma cells of the bone marrow that compromises the immune system and causes bone destruction. Approximately 6 per 100,000 persons are diagnosed, representing 1% of annual cancer incidence and 2% of cancer mortality.

In the United States, an estimated 26,850 persons will be diagnosed and 11,240 will die of myeloma in 2015. Since 1998 the five-year survival rate has improved from 28% to 47% but the outlook for patients with high-risk myeloma has changed little.

About the CrowdCare Foundation and its Myeloma Crowd Research Initiative (MCRI): The CrowdCare Foundation is a patient-driven non-profit organization with programs that focus on education and supporting multiple myeloma patients. The Myeloma Crowd Research Initiative (MCRI) is a crowdsourcing collaboration of patients and medical researchers to select and fund research projects in high-risk myeloma. Myeloma Crowd Radio, an internet-based radio program, has conducted more than 60 interviews with myeloma experts from throughout the world since July 2013, providing patients everywhere in-depth, current and accessible information about the latest therapies and future prospects in myeloma research and treatment.

Website: www.myelomacrowd.org; Facebook: www.facebook.com/myelomacrowd; Twitter: @myelomacrowd.

Save the date....

November 19, 2015 Living Well with Myeloma Teleconference Series presents – [Myeloma 101-Updates on Treatment & Pain Management](#). Register on the IMF website today.

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

UW Carbone Cancer Center

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