



“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 June 17, 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

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 write of our group member, Norward Steffen passing away on May 22, 2014. Norward and Tamara joined our group in November 2006. When they could, they attended meetings in Madison. Norward had a difficult time getting a proper diagnosis. Once he did, he took every opportunity to try clinical trials. He worked hard to regain his strength and independence to live a normal happy life. He was quick to share all he knew about this disease to help others. We will miss him. Our sympathies go out to Tamara and family.

June’s meeting speaker is from SHIP (State Health Insurance Program), Jill Helgeson, Medigap Counselor. The program is entitled “Fitting the Pieces around Medicare”. Our group member, Mary Polancih was very impressed with what she learned and asked if they could present to our group.

Recap of our May meeting with Sue Enright, IMF Midwest Regional Director for support groups.

Sue gave us an update on the Black Swan initiative. She also explained what MRD-Zero was all about. Minimal Residual Disease is a measure of residual clones. These cells make up the MRD factor. Currently the Black Swan Initiative is using ultra-sensitive tests to accurately measure MRD; Flow Cytometry, DNA and PET/CT scanning. When flow, DNA and PET/CT are all negative, you have achieved MRD-Zero. Sue shared her personal experience with Dartatumab. (See information below.) Sue’s husband Rob is currently taking this new drug with good results.

Sue also acknowledged the group’s upcoming 15yr anniversary. Our group’s first meeting was September 21, 1999. Jane Buffett, Nancy Schulz and Chuck Koval were the founding leaders. Sue, Thank you and the IMF for the anniversary cake and gift card. It is appreciated.

In case you missed it...Dr Marc Siegel reports on Fox News May 16, 2014

Doctors at the Mayor Clinic have apparently cured a woman's late-stage blood cancer – the miracle drug? A large dose of the measles vaccine.

“People would think this is bizarre. This is actually right where science is these days, and it's extremely exciting. We're using the immune system and viruses to attack cancer,” Dr. Marc Siegel told Bill Hemmer this morning on America's Newsroom.

Twenty-four years ago, a research scientist at the Mayo Clinic started working on this particular vaccine, and has now found a way to make it work.

Dr. Siegel explained the vaccine is effective “because the measles virus loves the bone marrow.” Researchers gave patients with multiple myeloma the vaccine 10,000 times the normal dose, and then got the engineered viruses to go inside the cancer cells and kill them. Read more about the study on FoxNews.com

In a breakthrough that could offer new hope to people with some kinds of cancer, Mayo Clinic researchers say they managed to wipe out a woman's cancer with a blast of measles vaccine strong enough to inoculate 10 million people.

The 50-year-old woman's blood cancer, which had spread through her body, went into complete remission after the vaccine dose and Stacy Erholtz has been clear of the disease for more than six months.

"It's a landmark," lead researcher Dr. Stephen Russell tells the Minneapolis Star Tribune. "We've known for a long time that we can give a virus intravenously and destroy metastatic cancer in mice. Nobody's shown that you can do that in people before." And Erholtz's take on the approach is more than positive: "It was the easiest treatment by far with very few side effects. I hope it's the future of treating cancer infusion." The trial involved two patients with multiple myeloma, and the second failed to go into complete remission, with the cancer returning after nine months.

KARE-11 reports the trial involved patients with multiple myeloma because their immune systems are so compromised they lack the ability to immediately fight off the measles, giving the virus time to attack the cancer; they also had no conventional treatment options left.

Russell explains how the process works in layman's terms: "It puts the virus into bloodstream, it infects and destroys the cancer, debulks it, and then the immune system can come and mop up the residue." Up next: larger-scale studies, and tests of the vaccine's effectiveness against ovarian, brain, head, and neck cancers, as well as mesothelioma.

They also plan to test vaccines for viruses other than measles, with the goal being to find a "single-shot" cure for many cancers.

Daratumuma shows promising results.

Over the last 2 years, an anti-CD38 monoclonal antibody daratumumab (DARA) has emerged as a breakthrough targeted therapy for patients with MM. Early-stage clinical trials have found DARA to be safe and to have encouraging clinical activity as a single agent and in combination with lenalidomide in heavily pretreated, relapsed patients in whom other novel agents (such as bortezomib, thalidomide and lenalidomide) as well as stem cell transplant has already failed. DARA may, therefore, be the first mAb with significant anti-MM activity both as a monotherapy and in combination. It is currently being further evaluated both alone and in combination with conventional and novel anti-MM agents as part of prospective clinical trials.

Closing thoughts... What to Do in the Darkness

By Marilyn Chandler McEntyre - Weavings

Go slowly
Consent to it
But don't wallow in it
Know it as a place of germination
And growth
Remember the light
Take an outstretched hand if you find one

Exercise unused senses
Find the path by walking it
Practice trust
Watch for dawn

From The Rev. David C. Couper
St Peter's Episcopal Church
North Lake, Wisc.

From the PMMNG group (This is worth watching!)

A fellow myeloma patient shared this short 3-minute TED talk with me and I instantly wanted to pass it along to all of you. Although there is no one way to cope with Myeloma, this particular approach really moved me. Although the speaker does not have Myeloma, I think you'll see what I mean.

http://www.ted.com/talks/stacey_kramer_the_best_gift_i_ever_survived

Save the dates...

Myeloma Update 2014 ASCO/EHA/IMWG

June 26, 2014 6:00pm Central Time.

For those without internet access, register by calling 1-800-452-2873

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>

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 www.themmrf.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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