



“Providing an opportunity for multiple myeloma patients and their loved ones to come together to exchange information for mutual support, comfort, and friendship”

Meeting: **In person meetings will resume when we are allowed to gather at the address below.**

451 Junction Road
Madison, WI
UW West Clinic Room 1287

Enter the clinic... turn left and walk down a short hall...turn left again and conference room 1287 is the last one on the left.

Group Information:

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Madison Multiple Myeloma Support Group website
madisonmultiplemyeloma.org

Mailing Address: Wisconsin Multiple Myeloma Support Group
3309 Chicago Avenue Madison, WI 53714-1815

Information Sources :

International Myeloma Foundation (IMF)
Phone: 800 - 452 - 2873
Email: TheIMF@myeloma.org
Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
Phone: 203 - 972 - 1250
Email: info@themmrf.org
Website: www.multiplemyeloma.org

Myeloma Crowd /Health Tree Foundation
P.O. Box 1286
Draper, UT 84020
www.myelomacrowd.org

April 2022 Myeloma Newsletter

Upcoming Meeting Speakers

Christine Nielsen, M. A., Manager of Patient and Community Outreach for the Leukemia & Lymphoma Society will be our featured speaker at the May meeting. She will be giving an overview of the resources and services that the LLS has to offer. She will start at 3:30pm and leave plenty of time for Q & A.

Nancy Bruno, IMF Regional Director for Support Groups will be our June speaker. Topic to be determined later.

Dr Timothy Schmidt, UW Carbone Cancer Center will be our featured speaker for the July 19th meeting. He will be presenting information related to chromosomes and genetics.

Kimberly A. Gibbs RN, BSN, OCN.,Patient Advocacy Liaison from Takeda Oncology will be our featured speaker for the August meeting. Topic to be determined later.

Dr Aric Hall from the UW Carbone Cancer Center will be our featured speaker for the April 19th meeting. He will do his usual Q & A session. Mark your calendars now so you don't miss this meeting. He will join us from 4:30pm – 5:30pm.

When will we resume in-person meetings?

This question has come up several times over the last couple of months. I have reached out to someone who works in the East UW clinic and is a group member. As I learn more, I will update the group.

Our previous room at the UW West clinic was one of the largest rooms that they have. But the size would still make social distancing a challenge. My biggest concern is that the Pediatric clinic is right out in front of this room. Our youngest of children are just now becoming eligible for vaccines.

Some group members have asked if there could be a dual meeting.... in-person and virtual at the same time. I am hoping that group member, Allen could shed some light on how we could pull that off.

I haven't forgotten about those members who see the benefit from meeting and talking in person to others. We just need to be safe about this.

How to Determine Whether or Not a Stem Cell Transplant is Successful with Dr. Guido Tricot

To read the full article go to the Myeloma Crowd by Health Tree website. I have included a shortened version because I thought the explanations for Low, Intermediate and High Risk definitions were worth noting.

STANDARD-RISK VS HIGH-RISK MULTIPLE MYELOMA

In order to understand why a stem cell transplant might work better or results might be more durable in some patient populations, you need to understand how patients groups are classified as standard-risk and which are classified as high-risk.

Myeloma is such an individual disease that you need to understand the genomic chaos of the disease in order to understand your risk.

This genomic chaos is found in cytogenetics or chromosomes of the individual's myeloma. The different chromosomes can experience tremendous amounts of genetic changes, which is what makes assessing myeloma more complicated than other tumor-based cancer diseases.

LOW RISK

Patients who have low stage ISS I (low tumor load) and normal FISH cytogenetics are classified as having low-risk myeloma.

- Low/standard risk FISH cytogenetics include translocations 11;14, 6;14, and 12;14. Most myeloma patients are diagnosed with low to standard risk myeloma.

INTERMEDIATE RISK

Myeloma patients that are diagnosed with ISS III staging but who have normal FISH cytogenetics (listed above) are classified as intermediate risk.

Patients diagnosed with ISS I Staging who have high-risk FISH cytogenetics are classified as having intermediate-risk myeloma.

- High-risk FISH cytogenetics include deletion 17p, deletion 13, translocations 4;14, 14;16, 14;20, and multiple copies of chromosome 1q.

HIGH RISK

Patients who are diagnosed with ISS III staging and have high-risk FISH cytogenetics (mentioned above) are classified as having high-risk multiple myeloma.

ARE COMPLETE REMISSIONS NECESSARY?

While it's very important for those with high-risk myeloma to achieve complete responses and achieve MRD negativity, this isn't necessary for those with low/standard-risk disease. Only 13% of myeloma patients are classified as high risk. Eighty-seven percent (87%) have low or standard risk myeloma.

For the low-risk multiple myeloma population, achieving stringent complete response (sCR) is not statistically significant in indicating overall survival.

In fact, some myeloma patients with low-risk disease, especially those who have translocation 11;14, don't achieve MRD negativity easily and might not even ever achieve a complete response, but nevertheless do very well on treatment.

In 1989, in the Total Therapy 1 Trial, 13 patients who completed a stem cell transplant *never achieved a complete response* but were able to celebrate a high quality of life with stable disease for more than TWENTY years of progression-free survival.

There are a couple more updated booklets from the IMF-

“Kyprolis (Carfilzomib) injections” and “Understanding the Immune System in Myeloma Patients”.

Also, “Understanding VRD Regimen for Newly Diagnosed Patients”.

I have asked my IMF contact about an booklet on “Chemo Brain”. Hopefully, more info to come on that request.

Our virtual meetings are on the Zoom platform.

The meeting for April 19, 2022 will be from 4:00pm to 5:30pm featuring Dr Aric Hall from the UW Carbone Cancer Center at 4:30pm.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQQU2FOZ1hMUKFaRmJBc0Qzdz09>

Meeting ID: 844 5766 7535

Passcode: 678275

One tap mobile

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+1 253 215 8782 US (Tacoma)

+1 346 248 7799 US (Houston)

+1 669 900 9128 US (San Jose)

Meeting ID: 844 5766 7535

Passcode: 678275

Find your local number: <https://myeloma-org.zoom.us/j/84457667535>

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 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” and sent to UW Carbone Cancer Center, University of Wisconsin Foundation, 1848 University Ave, Madison, WI 53726. Donations may also be made online at www.supportuw.org/give (Trillium Fund in Multiple Myeloma Research – 112903576). For any questions, please call Daniel Rosen at (608) 264-5437 or email curecancer@supportuw.org.