



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

Meeting: **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

April 2021 Myeloma Newsletter

Upcoming speakers-

Dr Timothy Schmidt, from the UW Carbone Cancer Center will be our featured speaker for the May virtual meeting. He will be talking about genetics and chromosome testing and what it all means.

Michelle Lakner, Nurse Practitioner for the UW Carbone Cancer will be our featured speaker at July's meeting. More information to follow. I will be collecting questions ahead of this meeting. Those questions will become the starting point of her Q & A .

Dr, Aric Hall from the UW Carbone Cancer Center will be our featured speaker for the April virtual meeting. Dr Hall does a Q & A session and it has become one of our favorites. Mark your calendars now not to miss this meeting. He will be joining us at approx. 4:30pm.

Register now from the Myeloma Crowd site for a presentation on April 15:
[Those Pesky Bone Hardeners! MM Patients Beware with Dentist Dr. John Killip](#)

From the IMF website – Two more drugs with FDA approvals.

On February 26, the Food and Drug Administration (FDA) [approved melphalan flufenamide \(Pepaxto®\)](#) in combination with dexamethasone for the treatment of relapsed or refractory myeloma in patients who have received at least four lines of prior therapy, including an IMiD, proteasome inhibitor and a CD38-directed monoclonal antibody.

According to the March 1, 2021 issue of the Journal of Clinical Oncology, Pepaxto® is a next-generation nitrogen mustard agent, a first-in-class agent evaluated in the phase II HORIZON trial. [The trial](#) involved 157 patients and resulted in an overall response rate of 29% and PFS (progression-free survival) of 8.5 months in responding patients. The safety profile was acceptable and the conclusion from lead author Dr. Paul Richardson is that Pepaxto is an important new treatment for patients for relapsed or refractory disease. Results are being further evaluated in the OCEAN randomized trial, in which results are compared to pomalidomide plus dexamethasone.

On March 31, 2021, the Food and Drug Administration approved isatuximab-irfc (Sarclisa, sanofi-aventis U.S. LLC) in combination with carfilzomib and dexamethasone, for the treatment of adult patients with relapsed or refractory multiple myeloma who have received one to three prior lines of therapy. More information is on the IMF website at www.myeloma.org.

What Is Ide-Cel? Dr Durie discusses this in one of his podcasts which is available on the IMF website.

Ide-cel is a promising new therapy where a third of patients reported an average treatment-free remission period of 19 months. It is currently under review by the FDA.

Here is some of the transcript from that session.

This is a type of CAR T-cell therapy. Patient's t-cells are harvested and then engineered over a period of a week or two, to target the myeloma cells. Targeting an antigen on the surface of myeloma called B-cell maturation antigen, BCMA. This is a type of therapy is called BCMA-targeted CAR T-cell therapy.

“A recent New England Journal paper, published on February 28th, the results of 128 patients who had received this ide-cel therapy were reported, and the results were quite promising. 73-percent of the patients had, at least, a partial response, and 33-percent of patients had a complete remission, or better. And, 26-percent of the patients had negative minimal residual disease at the ten to the minus five-level. And so, really excellent deep responses” reports Dr Durie.

The side effects were definitely manageable. This type of CAR T-cell therapy does have some special side effects including something called cytokine release syndrome, CRS. Only 5-percent of the patients did have this type of reaction, which can have some effects on the nerve tissue. This type of therapy also does cause a reduction in the blood counts at a significant degree for the first week or two until the blood counts have a chance to recover.

The average length of the remission was nineteen months. Patients receiving this therapy have been pleased that they are in remission for one year, two years, some even a little longer. And they're off therapy. And so, for the first time in many years, many patients are experiencing a treatment-free remission period, which is truly wonderful.

There is a lot of enthusiasm about this therapy. There's a lot of interest in; "what can we expect if this therapy could be introduced earlier in the disease course?" And so, a new trial, KarMMa-4 is getting started. And patients with high-risk myeloma, where the therapy will, in fact, be introduced much earlier reports Dr Durie.

I joined the Santa Fe Myeloma support group meeting this week for a session on Freelite testing. Got an interesting website for you. www.wikilite.com This has always been a confusing subject for many of us. Hope this helps.

Our meeting for April will be from 4:00pm until 5:30pm. Dr Aric Hall will be our featured speaker and will join us at 4:30pm.

At 4:00pm, group member, John has agreed to answer any questions from his personal experience with his Blenrep therapy. This has been a topic at the last several meetings.

IMF SG Meeting Room 3 is inviting you to a scheduled Zoom meeting.

Topic: Madison, WI SG 3rd Tue Monthly

Time: This is a recurring meeting Meet anytime

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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Dial by your location

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+1 312 626 6799 US (Chicago)

+1 646 558 8656 US (New York)

+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/u/kyMbCRs05>

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.