



“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:

Jayne Schwartz 608- 244-2120
schwartzdon@sbcglobal.net

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

October 2021 Myeloma Newsletter

Our October 19, 2021 meeting will feature Dr. Aric Hall from 4:30pm to 5:30pm. Dr Natalie Callander's patient schedule prevents her from starting at 4:30pm, so she may join Dr Hall after 5:00pm. This will be a Q & A session. Paul Westrick will be your meeting facilitator.

A big thank you to group member Pamela Wilson for her generous contribution to our support group. It is appreciated It will go along way towards the printing, postage and other mailings to current and new members. Again.. THANK YOU!

This subject has come up before about non-eligible transplant MM patients. What is the best option for them?

“Ask Dr. Durie”

A newly diagnosed, non transplant eligible patient tells Dr Durie that his doctor has recommended a treatment using the combination dex, daratumumab, lenalidomide. The question is: Is this a good option? Is this something he should go forward and use?

The answer to this question is a definite yes. The results with this combination in older patients who are not eligible for transplantation for autologous stem cell transplant have been usually good.

Professor Thierry Facon from France presented the updated result with this regimen at the recent European Hematology Association meeting that was held virtually.

He presented the results showing that the first remission using this three-drug combination was more than five years. So, a long first remission using this combination, and the overall survival was also excellent at five years with 66.3%. Probably the best results that we have seen with any combination in this non-transplant setting.

So, talk to your doctor, work with your doctor on this, but certainly the new updated results strongly support this as an excellent choice, and the expectation is high that you can achieve an excellent remission and a sustained remission for several years.

Questions from patients to Dr. Durie posted, September 14, 2021

Iberdomide Demonstrates Ability to Overcome Resistance to Common Myeloma Therapies

A new drug called iberdomide when combined with daratumumab, bortezomib or carfilzomib is showing positive effects with fewer side effects than its predecessor drugs lenalidomide and pomalidomide, according to research presented at the IMW meeting in Vienna by Sagar Lonial, MD, FACP of Emory University.

Iberdomide is a new oral drug called a CELMoD. While it shares similarities with well known immunomodulator drugs lenalidomide and pomalidomide, it is a completely unique type of drug. Iberdomide binds to cereblon (CRBN) to help degrade target proteins Ikaros and Aiolos. Iberdomide both stimulates the immune system and has direct anti-myeloma killing abilities. **Importantly, it also works in patients who are resistant to lenalidomide and pomalidomide.**

Many patients who entered the study were already resistant to bortezomib or immunomodulators.

The patients were split into three study groups: Iberdomide/daratumumab/dex, Iberdomide/Velcade/dex and Iberdomide/Kyprolis/dex. One of the primary goals of the study was to determine the best dose when iberdomide was combined with the other myeloma drugs.

Outcomes of iberdomide in the various combinations were as follows:

	IberDd	IberVd	IberKd
Overall response Rate	45.9%	56%	50%
Stringent CR	2.7%		12.5%
Complete Response	5.4%	4%	
Very Good Partial Response	16.2%	24%	25%
Partial Response	21.6%	28%	12.5%
Minimal Response	8.1%	8%	
Stable Disease	35.1%	24%	37.5%
Progressive Disease	10.8%	8%	12.5%

Dr. Lonial concluded his presentation by stating that iberdomide was promising for patients in these combinations even for patients who were refractory to commonly used drugs like proteasome inhibitors, immunomodulatory drugs and CD-38 antibodies.

Myeloma patients are always happy to see more effective drugs with a lower side effect profile in development. We look forward to iberdomide running through Phase III studies and will follow the progression.

Posted - Oct 7th, 2021

From Myeloma Coach by Health Tree..

The **Myeloma Coach** program offers peer to peer support from volunteer Myeloma Coaches who are either a myeloma patient or caregiver.

Not everyone is able to attend a support group, and some would rather have personalized one to one support. The Myeloma Coach program offers personalized support from someone who can relate and understands what it's like to live with or care for someone with myeloma.

If you need assistance registering to become a Coach or in finding a Coach contact us at myeloma@healthtreecoach.org, or call 800-709-1113.

At the Patient/Caregiver Conference in Waukesha

Imerman Angels had a booth and was highlighting their service. They are another resource to contact for one on one peer support. They represent all cancers but can find Myeloma coaches and caregivers. If you are interested, just give them a call at 1-866-Imerman (463-7626). More information on their website at www.ImermanAngels.org

Our virtual meetings are on the Zoom platform.

Our meeting for October 19, 2021 will be from 4:00pm to 5:30pm Paul Westrick will be your meeting facilitator.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQ2FOZ1hMUkFaRmJBc0Qzdz09>

Meeting ID: 844 5766 7535

Passcode: 678275

One tap mobile

+13017158592,,84457667535#,,,,*678275# US (Washington DC)

+13126266799,,84457667535#,,,,*678275# US (Chicago)

Dial by your location

+1 301 715 8592 US (Washington DC)

+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.