



“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

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

New resource addition above.

July 2021 Myeloma Newsletter

Upcoming speakers-

Dr. Natalie Callander from the UW Carbone Cancer Center will be our featured speaker at our October meeting. More information to follow.

Michelle Lakner, Nurse Practitioner for the UW Carbone Cancer will be our featured speaker at July's meeting. She will be joining us at 4:30pm. Mark your calendar's now!

A big thank you to Kathy and Fred for their generous contribution to the support group. It is appreciated and will be used for the postage and printing distribution of the newsletter.

Our IMF Support Group rep, Kelly Sidorowicz has created guided audio meditation and yoga videos as part of the Myeloma March Awareness campaign. These interactive programs are free and very interesting. I listened to the meditation one and tried the chair yoga. It is not as easy as you think. Word to the wise... do not do the chair yoga in a rolling office chair! Not a good idea. Check them out. She did a nice job! mam.myeloma.org/min-and-body

If you have access to the IMF website, they have recently updated their **“Myeloma Terms and Definitions”** guide. I have used the previous guide many times but this one is much more comprehensive and up to date. Search for it on the IMF website. For those newsletter folks on my emailing list, it is attached. I am sending this again as some folks reported that they did not get it.

We have a new Takeda Support Group rep, Matt Thompson. Wilbur Baker (former rep) and Matt are looking to see if there is a stash of the Takeda Cook books available. I could be getting a shipment soon. More info to follow.

From the Myeloma Crowd website – an update on

A Skin Patch Administration of Lenalidomide in Multiple Myeloma?

Myeloma patients are familiar with the drug Revlimid (lenalidomide) and with the side effects of the drug – especially during the early period of treatment.

Some of Revlimid’s side effects or severity of its side effects are most likely coming from the once daily dosing. Revlimid has a very pronounced “peak to trough” after dosing. What that means is that, after the drug is taken, it builds up very rapidly to a peak concentration in the circulating blood typically between 0.5 – 6 hours post dosing, with a half-life of 3 hours and then it drops off very rapidly.

Just about all pharmaceuticals come with side effects and, typically, those are most prevalent around the time that the drug is peaking in the system. Pharmaceutical companies will try and work around such peaks by formulating drugs so that the total therapeutic drug load delivered to the patient is spread over a longer period of time but with a release profile that lowers the “peak”. Sometimes this is done to provide dosing convenience to the patient (and, e.g., change dosing from multiple “pills” per day to a single daily dose).

Starton Therapeutic has announced that they have developed multiple transdermal [through the skin] formulation candidates of lenalidomide.

The company states:

*“STAR-LLD is a proprietary, medicated, adhesive patch placed on the skin to deliver lenalidomide continuously at the optimal dose using up to **90% less drug** when compared to approved oral formulations.”*

Current FDA regulations allow for a shorter product development program as there will be no need to

repeat the pre-clinical safety and toxicology studies of this drug that has been used now in the US for the past 14 years. The company intends to start its clinical programs in the not-too-distant future. This is a potentially interesting development to monitor over the next few years.

Co-pay assistance programs update as of June 7, 2021:

The **Healthwell Foundation** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit this **Healthwell Foundation page**.

The **Patient Advocate Foundation (PAF)** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit the **PAF page**.

The **Leukemia & Lymphoma Society (LLS)** has available funds for their co-pay assistance program. To learn if you qualify and how to apply, visit this **LLS page**

However, many other co-pay assistance programs are still unable to assist patients. If you have an existing grant, please check its status with that co-pay foundation. Links provided below:

[CancerCare](#), [Good Days](#), [PAN pag](#)

If you are in need of co-pay assistance, we also encourage you to contact the patient support programs of the drug manufacturers directly:

Amgen

- Kyprolis
- Amgen Assist 360 Program

Bristol Myers Squibb

- ABECMA®
- Cell Therapy 360
- Thalomid (Thalidomide)®, Revlimid® (lenalidomide) and Pomalyst® (pomalidomide)
- BMS Access Support

GlaxoSmithKline

- BLENREP (belantamab mafodotin-blmf)
- GSKForYou | Patient Assistance Program

Janssen

- DARZALEX® (daratumumab)
DARZALEX FASPRO® (daratumumab and hyaluronidase-fihj)
- Janssen CarePath Program

Karyopharm

- XPOVIO® (selinexor)
- KaryForward® Patient & Caregivers Support

Oncopeptides

- PEPAXTO® (melphalan flufenamide)
- ONCOURSE with Oncopeptides

Sanofi Genzyme

- SARCLISA® (isatuximab-irfc)
- CareASSIST Patient Support Program

Takeda

- Takeda Oncology Here2Assist™
- Velcade Support

Our virtual meetings are on the Zoom platform.

Our meeting for July 20th will be from 4:00pm until 5:30pm. Michelle Lakner will join us at 4:30pm.

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=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

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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/j/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.