



“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:

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

May 2022 Myeloma Newsletter

Upcoming Meeting Speakers

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.

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.

Cookbooks have arrived!

I have just received some more cookbooks from Takeda. The cookbook could offer some help to those who are struggling to eat well during chemo or transplant therapy. Let me know and I can either send you a copy or drop one off.

New and Updated IMF Publications in 2022: -

- Guide to Myeloma Terms and Definitions
- Patient Handbook
- Adherence to Oral Cancer Therapy
- Bispecific Therapy
- Early Warning Signs of Myeloma
- Kyprolis
- Sarclisa
- What is Myeloma? What is the IMF?
- Understanding – Abecma
- Understanding – Darzalex and Darzalex Faspro
- Understanding – The Immune System in Myeloma
- Understanding – Kyprolis
- Understanding – The VRd Regimen for Newly Diagnosed Myeloma

All are available on the IMF website in PDF format.

From the IMF - First Generic Revlimid (lenalidomide) Launched

On March 7, 2022, Teva Pharmaceuticals announced the launch of the first generic version of REVLIMID® (lenalidomide) in the US, with dosages available at 5mg, 10mg, 15mg, and 25mg capsules.

This announcement has led to considerable interest and many questions from the myeloma community. The main questions revolve around costs of the generic lenalidomide, but there were also questions about the generic version's efficacy and potential side effects compared to the brand product, Revlimid.

What we know right now- The amount of generic lenalidomide currently available is expected to be volume-restricted and to increase slowly over time, until the volume restrictions are removed on January 31, 2026.

The volume-limited selling of generic lenalidomide is now allowed to occur (after March 2022) contingent upon approval of an abbreviated New Drug Application. **Reports indicate that FDA approval was obtained in 2021 by two pharmaceutical companies: Natco Pharma Ltd. (working with Teva) on May 21, 2021; and Dr. Reddy's Laboratories Ltd. on October 14, 2021.** This FDA approval is important for patients because generics go through a rigorous review process. **The FDA requires that a generic product must provide the same clinical benefit and safety as the brand product (Revlimid, in this case).**

Teva is primarily a drug supplier selling lenalidomide to wholesalers, who then sell to specialty and retail pharmacies

This means that the pharmacies are the main source of pricing information for patients.

Availability of generic lenalidomide varies from state to state. **The way the prescription is written will allow substitution of generic lenalidomide for the brand Revlimid, or specification of one over the other. In some states, if no selection is made, the patient can choose.**

For patients with commercial insurance, they can go to the TEVA GENERICS site and access a co-pay card. However, it is important to note that generic lenalidomide is not yet on insurance company formulary lists.

The standard Risk Evaluation and Mitigation Strategy (REMS) questionnaire program will continue to be managed by BMS and will be required for prescriptions to be filled in the usual fashion.

What we do not know: The cost

As of now, we DO NOT know yet what the cost of generic lenalidomide for patients will be, versus the brand product, Revlimid.

Patients with commercial insurance can apply for a co-pay card, with an annual benefit of \$15,000 and a \$10 co-pay cost per prescription for brand Revlimid. Thus, it seems unlikely that the cost of generic lenalidomide will be significantly less.

For Medicare patients, **the co-pay costs for Revlimid could end up being in the \$11,000 or higher range/year, depending upon an individual's Part D plan and whether they are eligible for grants from co-pay assistance foundations.** It's not clear yet if or how this changes with generic lenalidomide.

The bottom line- Our IMF InfoLine Coordinator, Judy Webb has been diligently researching for more definitive information about the pricing of generic lenalidomide. It seems that we will only be

able to find out the cost when patients start picking up and paying for generic lenalidomide prescriptions.

It is also still unknown if there are cost savings for wholesalers and/or pharmacies but if so, then, insurance formularies could make the switch over time.

This summary will be updated as more information becomes available. Meanwhile, any feedback from patients who have been prescribed generic lenalidomide will be greatly appreciated. If you have been prescribed generic lenalidomide and want to share your experience with the IMF, please email jwebb@myeloma.org.

Our virtual meetings are on the Zoom platform.

Our meeting for May 17, 2022 will be from 3:30pm to 5:30pm featuring Christine Nielsen, M. A., Manager of Patient and Community Outreach for the Leukemia & Lymphoma Society

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/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.