



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

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Information Sources :

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Website: www.myeloma.org

Multiple Myeloma Research Foundation(MMRF)
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Myeloma Crowd /Health Tree Foundation
P.O. Box 1286
Draper, UT 84020
www.myelomacrowd.org

August 2023 Myeloma Newsletter

Upcoming Meeting Speakers

Dr Natalie Callander will be our featured speaker September 19th . Hope to get an update on the Trillium Research work.

MMRF nurse navigator will present at the March 2024 meeting. More info to follow.

Our condolences go out to the families of Mary Lind and Jay Burroughs

Jay passed away July 10, 2023. Jay joined our group March 2019. He did attend some of our meetings and freely shared his experiences.

Mary passed away March 20, 2023. She received our newsletters via mail and I don't have a date when she joined our group. I hope she found the newsletters to be helpful. I hope they gave her direction and information to be her best advocate.

I now have these educational tool kits.

The Multiple Myeloma Research Foundation has a new educational tool kit! I have requested 20 copies and will let you know when they are here. This will be helpful for newly diagnosed group members. It is titled “Your Myeloma Journey Guide”.

Included in the tool kit :

- Multiple Myeloma Treatment Overview
- Multiple Myeloma Disease Overview
- Caregiver Guide
- Precision Medicine Booklet
- Myeloma Booklet
- Autologous Stem Cell Transplantation Booklet
- Immunotherapy Booklet
- Patient Resource Guide

New testing information from the IMF

August 3, 2023

Dr Durie's blog on -Next Generation Testing

The introduction of better therapies that frequently produce very deep response has necessitated reliable monitoring at low levels of the disease, even beyond traditional complete response (CR). Two types of testing have been introduced to detect myeloma at these low levels of disease.

Next Generation Flow (NGF) and Next Generation Sequencing (NGS)

These are cellular tests that look for low levels of myeloma cells in the bone marrow and blood. This is called minimal residual disease (MRD) testing.

Next Generation Flow (NGF) will become commercially available for this assessment in 2024 in the U.S. NGF is used to determine the number of myeloma cells using a flow cytometry approach.

This method plus a related method called **Next Generation Sequencing (NGS)—a method that detects the specific gene sequence of myeloma cells the specific gene sequence of myeloma cells—have been used in the clinical trial setting for several years now.**

These tests are clearly valuable for the documentation of very deep response and in indicating that one treatment is better than the other in producing such deep responses (MRD undetected).

Mass Spectrometry

Mass spectrometry is a type of protein testing which uses very sensitive methodology to detect very low levels of myeloma protein in blood and urine.

Mass spectrometry has also been used in clinical trials for several years to assess response. When the mass spectrometry test (Maldi-TOF method) indicates a negative result, this correlates with a response that is somewhat better than CR using traditional SPEP and IFE testing.

The Maldi-TOF method will become commercially available in the U.S. in 2024, with the trade name, **EXENT method.**

A more sensitive method called Maldi-Q gives information similar to MRD testing and will become available in the future.

Bottom Line

Next Generation testing is almost here! However, standardization and guidelines are required to for doctors and patients to be able to interpret test results.

NGF guidelines need to be put in place to standardize the collection of samples for testing (sample acquisition) as well as all aspects of processing and reporting of results.

Fortunately, there is a software program which automates details of sample processing (called cell gating). However, right now there is no safeguard against the reporting of “**no myeloma detected**” which may be due to a poor-quality sample.

Guidelines for mass spectrometry are likewise required for doctors and patients to be able to compare what the advantages of mass spectrometry (EXENT method) are over traditional testing. Assessment of real-world and clinical trial data is required for best guidance.

Drug Classes Made Simple from the IMF (see the entire video on their website)

July 27, 2023 Overview

- Alkylators: Traditional form of chemotherapy used in multiple myeloma, including drugs like melphalan and cyclophosphamide.
- Proteasome Inhibitors: Drugs like bortezomib, ixazomib, and carfilzomib that inhibit the proteasome, leading to cell death. Can be effective in combination with other drugs but can cause neuropathy and drop blood counts.
- Immunomodulatory Drugs: Thalidomide, lenalidomide, and pomalidomide, which interact with myeloma cells and their environment. Side effects can include neuropathy, fatigue, and constipation.
- Monoclonal Antibodies: Daratumumab, Isatuximab, and Elotuzumab target specific molecules on the surface of myeloma cells, triggering the immune system to destroy them. Infusion reactions may occur during the first doses.
- XPO1 Inhibitors: Selinexor blocks the XPO1 pathway to prevent cancerous cell growth instead of it spreading. Side effects can include fatigue, nausea, vomiting, and decreased blood counts.

Our virtual meetings are on the Zoom platform.

Our meeting for August 15, 2023 will be from 3:30pm to 5:30pm. Since there is no scheduled speaker, this meeting will be a group share. Need questions answered? Great time to get some insight from our fellow group members.

Join Zoom Meeting

<https://myeloma-org.zoom.us/j/84457667535?pwd=V0lJTdNQU2FOZ1hMUKFaRmJBc0Qzdz09>

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 specialist 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 Janie Winston 608-512-6068 or email at Janie.Winston@supportuw.org.