

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR JANUARY 8, 2020

This was an open meeting:

Since we still had not received our supplemental funding from the IMF for refreshments for our monthly meetings, it was decided in December, that the January 8 meeting refreshments would be in the form of a "Pot Luck Dinner". What a success!! We had a wonderful assortment of appetizers, dinners, and desserts. Everything was delicious. Thank you to everyone who joined us!! Below were the topics of discussion...

We had a few folks not in attendance due to colds, hospitalizations, and a member in the beginning processes of a stem cell transplant. We wish them all well.

We also welcomed 2 new members.

INCLEMENT WEATHER NOTIFICATION

In the event of inclement weather on the evening of a support group meeting, a meeting cancellation notice will be posted on our web page (centralnj.support.myeloma.org) by 3:00 pm the day of the meeting, as well as on our Facebook page. All members will also be sent a meeting cancellation email by 3:00 pm the day of the meeting.

COLD/FLU SEASON

Please be mindful of cold and flu season. Protect yourselves by greeting others with "elbow bumps" rather than hugs, not only at our support group meetings, but also at all other times as well. As a tip from a former preschool teacher...besides hand washing, the use of saline nasal spray as well as a quick "deep" gargle with salt water or mouthwash, lessens the chances of air borne illnesses being able to attach to the mucous membranes of the nose and throat. Do this each time you return home from being out in public. When traveling by plane, try to book a window seat, and wipe down the chair, armrests, and tray with an antiseptic wipe. Wear a mask for your own protection. As a precautionary measure if you are not feeling well or have been exposed to the flu, please do not join us for our meetings. Many of our members have compromised immune systems which make them more susceptible. Masks will be available at our meetings for anyone interested in using one.

REFRESHMENTS

We have received our supplemental funding from the IMF for refreshments for our monthly meetings. As a quick recap, previously Takeda Pharmaceutical Co. provided our meeting refreshments, as well as covering about a half of the cost of our Spring Celebration of Life Event. Due to a change within Takeda, this is no longer the case. The IMF, has applied for Grants with Takeda Pharmaceutical Co. and Bristol Meyers Squibb (formerly Celgene), and all support groups were awarded supplemental refreshment funding. The amount of this funding will cover the cost of our monthly refreshments as well as paying for our Spring Celebration of Life Event. In order to utilize these funds in the best way possible, we have asked members to sign up for a refreshment month, and the member will be given money to purchase that meeting's refreshments. Please look for the sign-up sheet at our next meeting. (February's refreshments are accounted for),

ANNUAL SURVEY

The support group Annual Survey has been sent out to all members, as an email with a link to Survey Monkey. Please take a few minutes to complete this short survey, if you have not already done so. This survey is very important to Frank and I, and the Steering Committee, so we can plan this year's meetings around speakers that are of interest to you, and how our meetings are run. All responses are due on January 24, so that we can summarize the results and present them to the members present at our February meeting, and discuss the results further. Below is the link to the survey for your convenience.

<https://www.surveymonkey.com/r/JDCK2GS>

MARK YOUR CALENDARS!!!

March 4, 2020

Not only is March Myeloma Action Month, but at this support group meeting we will be celebrating the myeloma patient and caregiver. The theme of this meeting is...

“OUR SKILLS AND TALENTS ARE WHAT DEFINE US... NOT MYELOMA”

We are inviting all members to join us for a craft/hobby/art/talent exhibition. We would like you all to share with the group a talent that you possess. This can be in the form of art work, photos of your beautiful gardens or house plants, or maybe you knit, crochet, quilt, paint, or do wood working. Perhaps you enjoy cooking or participate in 5K races.

Bring photos of your talents! Each participating member will have their own table to display their talents. So, it is time to start thinking!! Maybe you do not have anything you feel is special to share...please feel free to join us, you may be inspired to try something new. We will discuss how these skills and talents make us more than a myeloma patient or caregiver. And as always, there will be time to get to know new members or address your concerns.

May 6, 2020

In lieu of this support group meeting, we will meet upstairs in the 3rd Floor Conference Room for our annual Spring Celebration of Life Event! At this Event, we will gather with our members, their families and close friends, and special invited guests, and celebrate life. This is a catered Event, with appetizers, dinner, dessert, and beverages being served at no cost to you. We will have a theme for our Celebration this year...

Resilience

“What is resilience? Resilience is adapting to adversity, trauma, of significant stress. Resilience is coming back from tough times to happier times. Resilience is the quality which allows us to carry on and deal with adversity”

We are requesting each member of our support group who will be attending the Spring Celebration of Life Event to bring a photo of something that makes them feel resilient. A picture that keeps you going in your myeloma journey...something that brings peace and hope. Also, you will be asked to write a brief summary of why you chose this particular photo. We will be displaying these photos and summaries at our Celebration. Frank and I experienced this “Wall of Resilience” at the Support Group Leaders Summit last year, and we cannot explain the emotion and strength we felt from each photo.

Below are informative links if you are interested...

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR JANUARY 8, 2020 INFORMATIONAL LINKS

International Myeloma Foundation

<https://www.myeloma.org/>

Best of ASH 2019 – What Patients and Caregivers Need to Know

<https://www.myeloma.org/videos/best-ash-2019>

Listen to audio replay and download slides

International Myeloma Foundation Patient Survey

The IMF is conducting this survey to better understand how patients with multiple myeloma and smoldering myeloma are treated

<https://www.research.net/r/IMFPatientSurvey>

Latest Multiple Myeloma News

<https://www.myeloma.org/cancers-news-events>

- **International Myeloma Foundation Partners with Medscape Oncology to Create Professional Education Series on Continuous Treatment in Multiple Myeloma**
- **International Myeloma Foundation Partners with Medscape Oncology to Create Professional Education Series on Continuous Treatment in Multiple Myeloma**

Co-pay Assistance Programs Update (12/10/19)

<https://www.myeloma.org/copay-assistance-update>

Ask Dr. Durie

<https://www.myeloma.org/imf-tv>

- **How will BMS's acquisition of Celgene impact the availability of drugs and services for myeloma patients?**
- **Should I have an autologous stem cell transplant (ASCT)?**
- **Is minimal residual disease (MRD) testing routinely recommended?**
- **Can bone lesions progress even when all other tests look good?**

IMWG Conference Series

<https://www.myeloma.org/imf-tv>

- Smoldering Myeloma: IMWG Conference Series ASH 2019
- Frontline Therapy: IMWG Conference Series ASH 2019
- Significance of FiSH testing: IMWG Conference Series ASH 2019
- CAR T therapy/Bi-specific T Cell engagers/MoAb: IMWG Conference Series ASH 2019 Orlando
- Novel Agents/Combinations: IMWG Conference Series ASH 2019 Orlando

Resources and Support

<https://www.myeloma.org/patient-caregiver-information>

- Caregiver Resources
- The IMF's InfoLine ...US & Canada: 800-452 CURE (2873)

Myeloma Today

A quarterly publication of myeloma research from our medical editors

Myeloma Minute

Receive the latest myeloma news and research for free, directly in your email inbox

Veterans Against Myeloma

<https://www.myeloma.org/veterans-against-myeloma>

Multiple Myeloma Research Foundation

<https://themmrf.org/>

Learn Your Labs

https://event.webcasts.com/starthere.jsp?ei=1278956&tp_key=e9cb6425be

Free Webinar

Tuesday, February 4, 2020
1:00 PM–2:00 PM (EST)

Dr. Craig Emmit Cole and Dr. Joshua Richter

MMRF CoMMpass Study

<https://themmrf.org/we-are-curing-multiple-myeloma/mmr-f-commpass-study/>

MMRF Immunotherapy Initiative

<https://themmrf.org/we-are-curing-multiple-myeloma/mmr-f-immunotherapy-initiative/>

MMRF Answer Fund

<https://themmrf.org/we-are-curing-multiple-myeloma/mmr-f-answer-fund/>

The MMRF Prevention Project

<https://themmrf.org/we-are-curing-multiple-myeloma/the-mmr-f-prevention-project/>

The Right Track

<https://themmrf.org/we-are-curing-multiple-myeloma/the-right-track/>

MMRF CureCloud

<https://themmrf.org/we-are-curing-multiple-myeloma/the-curecloud/>

MyDRUG

<https://themmrf.org/we-are-curing-multiple-myeloma/mydrug/>

The Myeloma Crowd

<https://www.myelomacrowd.org/>

- **ASH 2019: Chemotherapy Melflufen Moves Through Myeloma Clinical Trials**
- **Myeloma Highlights From ASH: Jack Aiello's Super Summary**
- **What is the Myeloma Crowd Research Initiative (MCRI)?**
- **Will A Failed Alzheimers Drug Further Improve Anti-BCMA CAR-T In Multiple Myeloma?**
- **ASH 2019: Minimal Residual Disease As A New Clinical Trial End Point**
- **1Q Gain Multiple Myeloma Is Sensitive To Specific Drug Targeting**
- **Patient Power: Myeloma Treatment In The Age Of Immunotherapies**

Health Tree

<https://www.myelomacrowd.org/healthtree/>

“ ...a revolutionary new patient-led community to improve myeloma patient outcomes and accelerate research...”

The Myeloma Crowd Research Initiative

<https://www.myelomacrowd.org/mcri/>

The Myeloma Crowd Research Initiative/Optimizing Myeloma Care

<https://www.myelomacrowd.org/mcri2/>

Life With Myeloma

<https://www.myelomacrowd.org/life-with-myeloma/>

- Repeating A First CAR-T Infusion In Multiple Myeloma
- Multiple Myeloma, Stem Cell Transplants And ...Shingles
- What Are Myeloma Crowd Round Tables?
- What Is The Myeloma Coach Program?

Myeloma Crowd Radio

<https://www.blogtalkradio.com/myelomacrowdradio>

Myeloma Beacon

<https://myelomabeacon.org/>

Myeloma Central

<https://www.myelomacentral.com/>

- Symptoms and Diagnosis
- Treatment and Monitoring
- Living With Multiple Myeloma
- Multiple Myeloma in African Americans

Cure

<https://www.curetoday.com/tumor/myeloma>

OncLive

<https://www.onclive.com/articles/myeloma>

- **Expert Highlights Research Developments Across the Spectrum in Multiple Myeloma**
- **Daratumumab-Based 4-Drug Induction Regimens Improve Outcomes in Myeloma**
- **FDA Approval Sought for Belantamab Mafodotin in Relapsed/Refractory Myeloma**
- **Novel Agents and Combos Continue to Transform Myeloma Paradigm**

Myeloma Research News

<https://myelomaresearchnews.com/>

- **Pivotal DREAMM-2 Trial Supports Belantamab Mafodotin's Use for Heavily-treated Multiple Myeloma**
- **Myeloma Patients in Phase 1 Trial Show High Response Rates with REGN5458 Treatment**
- **PNK-007 Treatment After Stem Cell Transplant Leads to Good Response Rates in Multiple Myeloma Patients, Early Trial Data Show**
- **Switching Chemo Types in Initial Combo May Help Myeloma Patients with Poor Response, Study Says**
- **Top 10 Multiple Myeloma Stories of 2019**
- **Advanced Multiple Myeloma Patients Responding to Janssen's CAR T-cell Therapy, Trial Data Show**

Myeloma Hub

<https://multiplemyelomahub.com/>

- **bb21217, An Anti-BCMA CAR T-cell Therapy, In Patients With R/R MM - Updated Results From Phase I Study**

- What are the most promising CAR T therapies in development for multiple myeloma?
- How significant is the role of MRD status in MM, and how can we best utilize this information?

Cancer.Com

<https://www.cancer.com/multiple-myeloma>

Cancer Support Community of Central NJ

<https://www.cancersupportcnj.org/>

American Society of Hematology

<https://hematology.org/>

Practice Update

<https://www.practiceupdate.com/explore/channel/oncology-multiple-myeloma/ut102-1>

Medscape

<https://search.medscape.com/search/?q=multiple%20myeloma&plr=all&page=1>

ASH Clinical News

<https://www.ashclinicalnews.org/?s=multiple+Myeloma>