

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR WEDNESDAY MARCH 4, 2020**

This was an open meeting...

We welcomed two new members.

This open meeting had the theme, “Our Skills and Talents are What Define Us...Not Myeloma!!” We had asked all members who wished to participate, to bring to the meeting, samples of their skills and talents. In keeping with the IMF’s “Resilience Theme” for March (Myeloma Action Month), we asked the participating members to also explain the importance of their skills and talents in their lives when describing what they decided to share with the group. In all we had 14 members share their talents with the group! This was such a wonderfully inspirational and interesting meeting. Frank and I wish we had another hour.

We had hoped to also ask the members in attendance who did not share a talent Wednesday evening, to speak about their thoughts regarding what keeps them strong during their myeloma journey. But we did run out of time. That being said, if you would like to speak about this at another open meeting, please do so!!

### **CORONOVIRUS**

This is a concern to many at this time, especially myeloma patients, their families and caregivers. Below are links to two blogs by Dr. Durie of the International Myeloma Foundation (which can also be found on the attached informational links page)

#### **Coronavirus and Myeloma Patient Safety**

<https://www.myeloma.org/dr-duries/coronavirus-myeloma-patient-safety>

#### **Coronavirus (COVID-19) Update: Elbows or Shoes, But No Handshakes!**

<https://www.myeloma.org/cure-blog/coronavirus-covid-19-update-elbows-or-shoes-no-handshakes>

Also attached is article that was found on one of the Myeloma Facebook pages, that has some useful information. **A few days after our meeting was held, the IMF issued a statement requesting no further in-person support group meetings for March. We have a speaker scheduled for April, and Frank will be reaching out to them to see if this could be in webinar form instead if need be. We will keep you all posted. Also, at this time, we are cautiously planning ahead with our Spring Celebration of Life Event, which was to be held in May. If necessary, this will be rescheduled as well.**

### **Amgen Round Table Discussion**

On February 29, Debbie and I had an opportunity to participate in a round table discussion sponsored by Amgen Pharmaceutical. Attending, were members of various support groups across the country, inclusive of leaders and individuals that were newly or recently diagnosed. Our own Larry and Linda Weiss attended and provided excellent input and we appreciate their attendance. The discussion focused on patient's ability to tolerate certain drug therapies, managing side effects, interest in clinical trials and the significance of participating in a trial when the opportunity presents itself to the appropriate patient. Clearly, to Debbie and I, Amgen was sincerely concerned in gaining the patients and caregivers perspective on a host of issues, that they could use to better serve their customers in the future. Having been part of several discussions hosted by Pharmaceutical Companies, each one was so patient focused, that there was a clear level of confidence they are working as diligently as possible to improve the quality of our lives.

### **SOME OUTDOOR EVENTS**

April 19 - Stroll the Shore for a Cure, Point Pleasant NJ

April 25 - Miles for Myeloma 5K, Philadelphia PA

September 26 - Miracles for Myeloma 5K, Clark NJ

We urge you all to take the necessary precautions during this Coronavirus outbreak, stay well, and we look forward to seeing you soon. If you should have any questions or concerns, please feel free to reach out to either Frank or I. You can send an email or call 908-876-3967.

Debbie Morell

Below is a listing of Informational Links if you are interested...

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR MARCH 4, 2020**

### **INFORMATIONAL LINKS**

#### **International Myeloma Foundation**

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

Coronavirus (COVID-19) Update: Elbows or Shoes, But No Handshakes!

<https://www.myeloma.org/cure-blog/coronavirus-covid-19-update-elbows-or-shoes-no-handshakes>

Coronavirus and Myeloma Patient Safety

<https://www.myeloma.org/dr-duries/coronavirus-myeloma-patient-safety>

International Myeloma Foundation Pleased to Announce FDA Approval of Sarclisa (isatuximab-irfc)

Phase III Boston Study Meets Its Primary Endpoint

Dr. Durie's Week in Review

- Understanding Resilience: A Resource to Help Meet Life's Challenges
- Don't freak out: start the new year healthy and positive

Ask Dr. Durie

- What can newly diagnosed myeloma patients expect in regard to treatment in 2020?

- Do fractures resulting from a fall indicate myeloma progression?

Black Swan Research Projects Forge Ahead in 2020

<https://www.myeloma.org/cure-blog/black-swan-research-projects-forge-ahead-2020>

March is Myeloma Action Month!

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

International Myeloma Foundation (IMF) Launches Resilience-Themed Campaign for Myeloma Action Month in March 2020

<https://www.myeloma.org/node/2554>

Understanding Resilience: A Resource to Help Meet Life's Challenges

<https://www.myeloma.org/hope-blog/understanding-resilience-resource-help-meet-lifes-challenges>

Co-pay Assistance Programs Update (2/11/2020)

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

The IMF Patient & Family Seminar in Boca Raton, Florida - **UPDATE!!!**

March 13-14

This has been changed from an on-site seminar to an **on-line seminar**

Visit <https://www.myeloma.org/events/2020-patient-family-seminar-boca-raton-fl-update> for more information

A 10-Day Luxury Hawaiian Oasis Is a Winning Raffle Ticket Away

<https://www.myeloma.org/hawaii2020>

## The Multiple Myeloma Research Foundation

<https://themmrf.org/>

### Myeloma News

<https://themmrf.org/about-mmrf/news-press/multiple-myeloma-news/>

- The Difference Between Cellular Therapy and Autologous Stem Cell Transplant
- Finding the Right Care for Myeloma

### Myeloma Crowd

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

- Staying on Road of Life in Spite of a Multiple Myeloma Diagnosis with the help of a Myeloma Coach with Doug Stewart
- Preventing Infections and the Coronavirus in Multiple Myeloma
- What is a Neutropenic Diet for Multiple Myeloma Patients?
- Why all Multiple Myeloma Patients Need a Myeloma Specialist
- Myeloma Specialist Directory
  - <https://www.myelomacrowd.org/myeloma-directory/>
- Muscles for Myeloma: Doing Something Is Better Than Nothing
- New CD38 Monoclonal Antibody Sarclisa® (isatuximab) Receives FDA Approval for Relapsed Multiple Myeloma
- Accelerating Multiple Myeloma Research with FREE HealthTree Surveys and Studies
- Better Gut Diversity Before Allo Transplant Lowers Death Rate for Blood Cancer Patients
- Anti-Nausea Effects of Ginger in Myeloma Care

- Plus More!

### **Myeloma Crowd Radio**

<https://www.myelomacrowd.org/myeloma-crowd-radio-episodes/>

- Full Show: Preventing Infections and Vaccination Recommendations After Myeloma Transplant with Jennifer Saullo, MD, PharmD, Duke University
- Full Show: Multiple Myeloma Progress for 2020 with Robert Orlowski, MD, PhD, MD Anderson Cancer Center
- Full Show: Myeloma Care in Patients Over 65 with Tanya Wildes, MD, Siteman Cancer Center

### **Myeloma Beacon**

<https://myelomabeacon.org/>

- Bristol Myers Squibb Reports Primary Results Of ELOQUENT-1 Study Evaluating Empliciti (Elotuzumab) Plus Revlimid (Lenalidomide) And Dexamethasone In Patients With Newly Diagnosed, Untreated Multiple Myeloma
- FDA Approves Sarclisa (Isatuximab-irfc) For Patients With Relapsed Refractory Multiple Myeloma
- Karyopharm Announces Phase 3 BOSTON Study Meets Primary Endpoint With Significant Increase In Progression-Free Survival In Patients With On

### **Cure**

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

- Overcoming Multiple Myeloma Takes One Patient to New Heights
- Exciting Treatment Options Being Developed in Multiple Myeloma

### **OncLive/OncLive Videos**

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

- Multiple Myeloma Articles
  - Novel Regimens Show Continued Improvements in Newly Diagnosed Myeloma
  - Research With BCMA-Targeted Agents, Venetoclax Appears Promising in Myeloma
  - Upfront Multidrug Regimens Prove Beneficial in Myeloma
  - Venetoclax Poised to Have Role in Myeloma, Despite Safety Concerns
  - Plus more!
- OncLive Videos
  - Dr. Tan on the Risk of Novel Coronavirus for Patients With Cancer
  - Therapeutic Inhibition of XPO1-Mediated Nucleocytoplasmic Transport With SINE Technology
  - FDA Approval in Myeloma, Priority Review in DLBCL, Application Accepted of a Biosimilar, and More
  - Treatment of Multiple Myeloma

## Myeloma Research News

<https://myelomaresearchnews.com/>

- Xpovio Combo Significantly Extends Survival in RRMM, Trial Results Show
- Loss of Specific Gene May Help Drive Myeloma Progression, Study Finds
- FDA Approves Sarclisa Combo to Treat Advanced Multiple Myeloma
- CLR 131 Helps Heavily Treated Multiple Myeloma Patients, Phase 2 Data Show

- New CAR T-cell Therapy Shows Early Promise Against Multiple Myeloma in Lab Study
- Darzalex Combo Leads to Durable Responses in Patients With Advanced Multiple Myeloma, Follow-up Data Show
- Kleo's KP1237 Therapy Soon Will Enter Clinical Testing, Following FDA's Grant of New Drug Status
- Phase 1/2 Trial of 'Off-the-shelf' CAR T-cell Therapy for Multiple Myeloma to Open Soon

## Myeloma Hub

<https://multiplemyelomahub.com/>

- GMMG-MM5 | Response-adapted lenalidomide maintenance in newly diagnosed multiple myeloma
- Carfilzomib, bendamustine, and dexamethasone (CBD) combination for patients with newly diagnosed multiple myeloma
- Dual-targeting CAR T-cell therapy for refractory multiple myeloma
- ASH 2019 | Practice-changing abstracts in multiple myeloma
- Implementation of CAR T-cell therapy in the real world - A round table discussion
- Cytopenia associated with CAR T-cell therapy
- Circulating tumor plasma cells as an independent prognostic marker for patients with MM
- Mutated lymphopoiesis and B cell oligoclonality can precede the pathogenesis of multiple myeloma and persist in patients with negative measurable residual disease

## HealthTree University Myeloma Videos

<https://www.youtube.com/channel/UC27i8v856WBGy-4ONPJS0MQ>

## **Myeloma Central**

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

## **Veterans Against Myeloma**

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

## **Standing in the Gaap**

<https://www.myelomacentral.com/multiple-myeloma-african-americans/what-is-standing-in-the-gaap/>

## **Cancer.com**

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

## **American Society of Hematology**

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

## **Ash Clinical News**

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

