

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP APRIL 3, 2019 MEETING RECAP**

This was an open meeting. We focused this open meeting on questions from our members in attendance, and the conversations that followed. Below are some important information and upcoming events. As was done last month, an attachment will be provided with interesting links for you to follow if you are interested.

### **UPCOMING EVENTS**

#### **MILES FOR MYELOMA**

The 2019 Miles for Myeloma 5K Run/Walk is a regional, family friendly 5K Run/Walk presented by the Philadelphia Multiple Myeloma Networking Group.

#### **Event Details**

**Where:** Memorial Hall/Please Touch Museum

4231 Avenue of the Republic  
Philadelphia, PA 19131

**Date:** April 27, 2019 8:30 a.m.

**Day of Registration/Check-in Opens:** at 7:15 a.m.

#### **SPRING CELEBRATION OF LIFE EVENT**

Our Support Group's **SPRING CELEBRATION OF LIFE EVENT** will take place on Wednesday, May 1, 2019, in place of our regular support group meeting. We will meet in the 3<sup>rd</sup> Floor Conference Room of Steeplechase Cancer Center. This is a catered event, free of charge, and your family, and close friends are invited.

**THIS YEAR WE WILL BE HAVING A 50/50! (AND MAYBE EVEN A RAFFLE). TICKETS WILL BE AVAILABLE THE NIGHT OF THE EVENT FOR \$5 EACH, SO IF YOU ARE FEELING LUCKY, BRING SOME CASH!!!**

**TIME: 6:00 PM – 8:30 PM**

An email invitation to our **Spring Celebration of Life Event** will be sent to you via email next week, with RSVP instructions. **SO, MARK YOUR CALENDARS!!!**

### **MIRACLES FOR MYELOMA 5K RUN/WALK RACE**

**When: Saturday, September 21, 2019**

**Where: Oak Ridge Park, Clark NJ**

The website for the Miracles for Myeloma 5K Run/Walk Race is now open!! You can sign up as a single participant, start your own team, or join the Group's team, **CENTRAL JERSEY MEMORIAL TEAM**.

[http://give.myeloma.org/site/TR?fr\\_id=1770&pg=entry](http://give.myeloma.org/site/TR?fr_id=1770&pg=entry)

### **PATIENT/FAMILY SEMINAR, SHORT HILLS, NJ**

**IMF Patient/Family Seminar, Short Hills NJ**

[www.myeloma.org/imf-tv](http://www.myeloma.org/imf-tv)

The IMF's Patient/Family Seminar was held this past weekend in Short Hills, NJ, and as always, was a fantastic event. The topics discussed by the presenters were informative and detailed. There were also numerous occasions to have your questions answered by the myeloma specialists in attendance during their panel discussions, as well as during the breakout sessions where one of the specialists met with small groups of those in attendance for an intimate discussion and question/answer session.

While the link is for "IMF TV" "videos from the Boca Raton Patient/Family Seminar", much of the covered material is the same from this past weekend's seminar in Short Hills, NJ. If you were unable to attend, please view them if you are interested. Below are some "tidbits" I also thought might be of interest from the seminar (The links will be on the attachment)

### **Dana Farber Cancer Institute**

- Tips for Managing Neuropathy
- Discovery of peripheral neuropathy cause suggests potential preventive measures
- Lebed Method: Simple exercises for cancer patients

### **Mount Sinai / Research for Multiple Myeloma**

- FoundationOneCDX / Foundation Medicine – Genomic Testing
- Why You Should Have Your Multiple Myeloma Genome Sequenced

### **Memorial Sloan Kettering Cancer Center**

- Cancer and Supplements

## **Headline » News**

- U.S. FDA Okays First Clinical Trial of An Allogeneic CAR T-Cell Therapy for Multiple Myeloma

<https://myelomabeacon.org/news/2019/04/05/allogeneic-car-t-cell-therapy-multiple-myeloma-clinical-trial/>

- In the News: New Drug Updates and Notes on the Environment

[www.myeloma.org/blog/dr-duries/new-drug-updates](http://www.myeloma.org/blog/dr-duries/new-drug-updates)

The good news on Selinexor, Dara subcutaneous, Farydak (Panobinostat), and the not so good news on Venetoclax, along with Dr. Durie's "notes" on the environment

- Cures Reported for Two Blood Diseases in One Week: Can Either One Be Applied to Myeloma?

[www.myeloma.org/blog/dr-duries/cures-reported-two-blood-diseases](http://www.myeloma.org/blog/dr-duries/cures-reported-two-blood-diseases)

Please remember to view the attached document for informative links and we are hoping to see you at the Spring Celebration of Life Event on May 1, 2019. Enjoy this beautiful Spring, baseball season, and wishing you all continued good health.

Debbie Morelli

**CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP  
MEETING RECAP FOR APRIL 3, 2019**

**INFORMATIVE LINKS**

**FROM THE IMF**

[www.myeloma.org](http://www.myeloma.org)

**Living Well with Myeloma - MGUS, Smoldering Myeloma, and Newly Diagnosed**

[www.myeloma.org/events/living-well-myeloma-mgus-smoldering-myeloma-newly-diagnosed](http://www.myeloma.org/events/living-well-myeloma-mgus-smoldering-myeloma-newly-diagnosed)

**Susie Durie and Brian G.M. Durie, MD, Receive a Joint Honorary Doctorate from Vrije Universiteit Brussel**

[www.myeloma.org/imf-cofounders-receive-honorary-doctorate-vub](http://www.myeloma.org/imf-cofounders-receive-honorary-doctorate-vub)

**In the News: New Drug Updates and Notes on the Environment**

[www.myeloma.org/blog/dr-duries/new-drug-updates](http://www.myeloma.org/blog/dr-duries/new-drug-updates)

## **Cures Reported for Two Blood Diseases in One Week: Can Either One Be Applied to Myeloma?**

[www.myeloma.org/blog/dr-duries/cures-reported-two-blood-diseases](http://www.myeloma.org/blog/dr-duries/cures-reported-two-blood-diseases)

## **Drug Reimbursement Information and Assistance**

[www.myeloma.org/online-resources/drug-reimbursement-information-assistance](http://www.myeloma.org/online-resources/drug-reimbursement-information-assistance)

## **Clinical Trials Fact Sheets**

[www.myeloma.org/clinical-trials/clinical-trials-fact-sheets](http://www.myeloma.org/clinical-trials/clinical-trials-fact-sheets)

## **Veterans Against Myeloma**

[www.myeloma.org/veterans-against-myeloma](http://www.myeloma.org/veterans-against-myeloma)

## **The Myeloma Minute**

Receive the latest myeloma news and research for free, directly to your email. Subscribe and receive weekly email newsletters with up-to-the 'minute' information about multiple myeloma.

[www.myeloma.org/latest-myeloma-news](http://www.myeloma.org/latest-myeloma-news)

## **Myeloma Today**

A quarterly publication of myeloma research from the IMF's medical editors

The IMF's quarterly journal features scientific and clinical news and stories about education and awareness programs, patient meetings, and advocacy activities. Available online and by mail.

[www.myeloma.org/multiple-myeloma-journals](http://www.myeloma.org/multiple-myeloma-journals)

## **Ask Dr. Durie**

[www.myeloma.org/imf-tv](http://www.myeloma.org/imf-tv)

- Why is 17p deletion (17p-) considered to be a poor prognostic factor for myeloma patients?
- Are there any updates about new drugs for myeloma patients?
- What is CRISPR technology and has there been an interest for it in the United States?

AND MORE...

## **OTHER WEBSITES**

- Myeloma Explained

[www.myelomaexplained.com](http://www.myelomaexplained.com)

- Myeloma Research News

[www.myelomaresearchnews.com](http://www.myelomaresearchnews.com)

- The Myeloma Beacon

<https://myelomabeacon.org/>

- Cure Today

[www.curetoday.com/tumor/myeloma](http://www.curetoday.com/tumor/myeloma)

- MMRF (The Multiple Myeloma Research Foundation)

<https://themmrf.org/>

- Patient Power

[www.patientpower.info/multiple-myeloma](http://www.patientpower.info/multiple-myeloma)

- Myeloma Crowd

[www.myelomacrowd.org](http://www.myelomacrowd.org)

- Myeloma Crowd Radio

[www.blogtalkradio.com/myelomacrowdradio](http://www.blogtalkradio.com/myelomacrowdradio)

- Myeloma Central



[www.myelomacentral.com](http://www.myelomacentral.com)

- OncLive

[www.onclive.com/specialty/myeloma](http://www.onclive.com/specialty/myeloma)

## **“TIDBITS” FROM THE PATIENT/FAMILY SEMINAR IN SHORT HILLS**

### **Dana Farber Cancer Institute**

Tips for Managing Neuropathy

[www.dana-farber.org/health-library/articles/tips-for-managing-neuropathy/](http://www.dana-farber.org/health-library/articles/tips-for-managing-neuropathy/)

- Discovery of peripheral neuropathy cause suggests potential preventive measures

[www.dana-farber.org/newsroom/news-releases/2017/discovery-of-peripheral-neuropathy-cause-suggests-potential-preventive-measures/](http://www.dana-farber.org/newsroom/news-releases/2017/discovery-of-peripheral-neuropathy-cause-suggests-potential-preventive-measures/)

- Lebed Method: Simple exercises for cancer patients

[www.dana-farber.org/health-library/videos/lebed-method--simple-exercises-for-cancer-patients/](http://www.dana-farber.org/health-library/videos/lebed-method--simple-exercises-for-cancer-patients/)

**Mount Sinai / Research for Multiple Myeloma**

[www.mountsinai.org/care/cancer/services/multiple-myeloma/research](http://www.mountsinai.org/care/cancer/services/multiple-myeloma/research)

### **FoundationOneCDX / Foundation Medicine**

- Genomic Testing

[www.foundationmedicine.com/about](http://www.foundationmedicine.com/about)

[www.foundationmedicine.com/genomic-testing](http://www.foundationmedicine.com/genomic-testing)

### **The MMRF**

- Why You Should Have Your Multiple Myeloma Genome Sequenced

<https://themmrf.org/2017/10/why-you-should-have-your-multiple-myeloma-genome-sequenced/>

### **Memorial Sloan Kettering Cancer Center**

- Cancer and Supplements

[www.mskcc.org/search?q=supplements](http://www.mskcc.org/search?q=supplements)