

# **Central New Jersey Multiple Myeloma Support Group Meeting Recap for October 2, 2019 (Plus Informative Links)**

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR OCTOBER 2, 2019**

We welcomed two new members to our group.

**Guest Speaker:** Corey Payne, Clinical Nurse Educator, Oncology, from Janssen Pharmaceutical Co.

Corey spoke to group, and presented a basic overview of multiple myeloma (disease pathophysiology, risk factors, testing, support) with emphasis on newly developed myeloma information. We would also like to thank Janssen Pharmaceutical for providing our refreshments for this meeting.

Below is additional information and upcoming events that may be of interest.

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

The Miracles for Myeloma 5K Run/Walk was held this year on September 21, 2019, and was another huge success!! As of October 9, 2019, \$80,701 has been raised!!! The weather was perfect and the attendance was phenomenal. The support from our Support Group is remarkable. Below is a breakdown of the numbers regarding our support group...

Central New Jersey Support  
Group Teams

<b>Team Information</b>	Participants Runner/Walking	Total Fees Paid	TotalConfirmed Gifts(\$)	Grand Total
Central Jersey Memorial Team	#VALUE!	1525	2015	3540
Guy's Guys	#VALUE!	1620	2945	4565
Marching for Michele	#VALUE!	540	1090	1630
Paddy Power	#VALUE!	545	760	1305
Team Believe	#VALUE!	1420	3380	4800
Team Charlie	#VALUE!	125	420	545
Team Cure!	#VALUE!	950	4445	5395
Team Graubard	#VALUE!	140	501	641
Team Novlette	#VALUE!	850	1385	2235
Team Paula	#VALUE!	190	1455	1645
Totals	#VALUE!	7905	18396	26301

As you can see, \$26,301 was raised by our Support Group!!! Donations will be accepted through December 18,2019. Visit the website at

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

To view photos of race day, visit...

[https://photos.shutterfly.com/story\\_invite/8826bc1e-25d6-4012-b283-64e08f516488?cid=SHARALLI&branch\\_match\\_id=533371754243307302](https://photos.shutterfly.com/story_invite/8826bc1e-25d6-4012-b283-64e08f516488?cid=SHARALLI&branch_match_id=533371754243307302)

**Raffle, Raffle, Raffle!!!**

<https://www.myeloma.org/hawaii2019>

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

The IMF is hosting a raffle for you to win a 10-day stay at the Villa Ono Oasis in historic Kailua-Kona, Hawaii.

8/16/19 – RULES UPDATE: the dates of your stay are not specific and will be set by mutual agreement and subject to availability of the property.

**Only 1000 raffle tickets will be sold @ \$50 each!**

**First-come, First-served.**

All proceeds will benefit International Myeloma Foundation Research and Programs.

The winners of this luxury package will receive:

- A 10-day stay at Villa Ono Oasis
  - Heated saltwater pool
  - 3 bedrooms, 2800 sq. ft.
- Business-class Airfare for Two on American Airlines to Kona, HI
- A Dolphin Swim Adventure for Two
- A Manta Ray Night Snorkel for Two
- A Scuba Instruction Package for Two

Raffle drawing October 23, 2019

**Thursday, October 17, 2019**

The Multiple Myeloma Research Foundation presents

New Drug Approval: What Does the Arrival of XPOVIO (selinexor) Mean for Multiple Myeloma Patients? (webinar)

[https://event.webcasts.com/starthere.jsp?ei=1261636&tp\\_key=4196762aef](https://event.webcasts.com/starthere.jsp?ei=1261636&tp_key=4196762aef)

4:00 PM–5:00 PM (EST)

### **October 19, 2019**

The MMRF Team for Cures 5K Walk/Run

<https://walkrun.themmrf.org/new-york-city>

Location: Pier 84 Hudson River Park

New York, NY

Program Start: 8:30 a.m.

### **October 26, 2019**

The Leukemia & Lymphoma Society (LLS) presents “Light the Night Walk” in Morristown, NJ

<https://www.lightthenight.org/events/morris-county>

Saturday at 4:30 pm

412 Mt Kemble Ave (off Rt. 202)

APX in Morristown, NJ

### **November 2, 2019**

MMRF Patient Summit - Philadelphia, PA

<https://one.bidpal.net/philadelphiasummit/welcome>

Register for Free Today!

Loews Philadelphia Hotel

1200 Market Street

Philadelphia, PA

Phone (215) 627-1200

### **ADVOCACY ALERT!!**

The International Myeloma Foundation's Advocacy Team is in need of your help. They would like to speak to Rep. Pallone (NJ District 6) regarding the Oral Parity Bill for MM Drugs on the Federal level, but cannot do so without a constituent from his district in attendance.

“The Sixth Congressional District of New Jersey includes two counties in Central New Jersey. It covers most of Middlesex County and a good portion of Monmouth County, including the Bayshore and twelve communities on the Atlantic Ocean. “

If anyone lives in this area but is not sure if their representative is Mr. Pallone visit...

<https://www.house.gov/representatives/find-your-representative>

**If you live in this District and are interested in helping please respond to this email ([centralnj@imfsupport.org](mailto:centralnj@imfsupport.org)) and we will get you in touch with the IMF Advocacy Team.**

Our next meeting will be held on November 6, 2019. Our guest speakers will be Dr. Cooper and Jackie Manago P.A. from the Rutgers Cancer Institute of New Jersey.

## INFORMATIVE/EDUCATIONAL LINKS

### IMF

<https://www.myeloma.org>

### Dr. Durie Blogs

<https://www.myeloma.org/week-review-dr-brian-gm-durie>

- New Drug Combinations Show Promising Results, an Orphan Drug Designation, and the FDA Speeds International Approvals
- New Drug Updates: GSK Announces Positive Results from anti-BCMA Immune Conjugate Trial

### Ask Dr. Durie

<https://www.myeloma.org/imf-tv?category=19>

- Will it be possible to prevent multiple myeloma?
- What new drug options will be available for patients with relapsed and refractory multiple myeloma in 2020?

### Caregiver Resources...Caregivers need care too

<https://www.myeloma.org/resources-support/caregiver-resources>

### Navigating the Affordable Care Act (ACA)

<https://www.myeloma.org/affordable-care-act>

### Report from the 2019 Summit of the Global Myeloma Action Network

<https://www.myeloma.org/global-myeloma-action-network-gman/report-2019-summit-global-myeloma-action-network>

The Myeloma Matrix 2.0 Smart Search...Clinical trials for multiple myeloma

<https://www.myeloma.org/clinical-trial-search>

Current FDA-Approved Medications

<https://www.myeloma.org/multiple-myeloma-drugs>

Co-Pay Assistance Update (as of October 1, 2019)

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

Myeloma Today

A quarterly publication of myeloma research. Visit below to subscribe

<https://www.myeloma.org/multiple-myeloma-journals>

## **The Multiple Myeloma Research Foundation**

<https://themmrf.org>

MMRF Research Programs Drives New Breakthroughs in Multiple Myeloma

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

Multiple Myeloma in African Americans

<https://themmrf.org/2019/08/multiple-myeloma-in-african-americans/>

MMRF CoMMpass Study: An Update

<https://themmrf.org/2019/08/mmrf-commpass-study-an-update/>

2019 IMW Patient Symposium - Updates from The International Myeloma Workshop

View Slides and video - <https://themmrf.org/multiple-myeloma/resources/patient-education-programs/>

## **The Myeloma Crowd**

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

- Navigating the Cost of Myeloma Medications
- IMW 2019: The New GSK Antibody Drug Conjugate In Myeloma
- IMW 2019: MRD And CAR T Cell Updates
- Melflufen In Multiple Myeloma Therapy – IMW 2019
- A Review Of The International Myeloma Workshop (IMW) In Boston (Sept 12-15, 2019) by Jack Aiello, Patient Advocate, Myeloma Survivor
- What Cells Keep Myeloma Growing? Myeloma Researchers Find A Target

## **Myeloma Crowd Radio**

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



- The World's Largest Myeloma Screening Study (PROMISE) with Irene Ghobrial, MD, Dana Farber Cancer Institute

### **The Myeloma Beacon**

<https://myelomabeacon.org/>

- FDA Approves Daratumumab For Transplant-Eligible Multiple Myeloma
- Genmab Announces U.S. FDA Approval of Darzalex (Daratumumab) In Combination With Bortezomib, Thalidomide And Dexamethasone For Frontline Multiple Myeloma

### **Myeloma Central**

<https://www.myelomacentral.com>

- Caregiver Corner
- Lifestyle and Nutrition
- Understanding Multiple Myeloma

### **Cure**

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

### **OnLive**

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

- Selinexor Improves Late-Stage Treatment Options for Multiple Myeloma
- Mounting Advances Make Waves Across Myeloma Spectrum
- Risk Patterns Prior to Progression From MGUS to Myeloma Call for Annual Assessments
- Daratumumab Plus Carfilzomib and Dexamethasone Improves PFS in Myeloma
- IMW 2019: Selinexor Triplet Highly Active in Relapsed Myeloma
- Anti-BCMA BiTE AMG 701 Shows Preclinical Promise in Multiple Myeloma
- Dr. Kumar Discusses Path Forward for Venetoclax in Myeloma
- Plus, interesting videos

## **Myeloma Research News**

<https://myelomaresearchnews.com>

- Aplidin Prolongs Survival and Time to Disease Progression in Heavily Treated Multiple Myeloma Patients, Phase 3 Trial Shows
- Bone Marrow Macrophages Could Predict Resistance to Velcade, Study Suggests

- Darzalex, Kyprolis, Dexamethasone Combo Extends Time to Disease Progression in Relapsed, Refractory Multiple Myeloma Patients, CANDOR Trial Results Show
- FDA Approves Darzalex Combo for Newly Diagnosed Multiple Myeloma Patients Eligible for Transplant
- CLR 131 Granted Orphan Drug Status in Europe for Myeloma Treatment
- Carsgen's CAR-T Cell Therapy Given Priority Designation in Europe for Multiple Myeloma
- Investigational Antibody GBR 1342 Receives Orphan Drug Designation for Multiple Myeloma
- Ygalo Continues to Show Promising Activity in Relapsed, Refractory Multiple Myeloma

## **The Multiple Myeloma Hub**

<https://multiplemyelomahub.com>

- IMW (International Myeloma Workshop) 2019 | Smoldering Myeloma
- IMW (International Myeloma Workshop) 2019 | Great debates in myeloma
- IMW (International Myeloma Workshop) 2019 | MRD in myeloma

**Cancer.com**

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

“At Cancer.com, we understand that there are a lot of cancer resources and information available across the Internet for you to look through. Finding what you are looking for can be overwhelming. That’s why Janssen Oncology began working with highly respected cancer organizations—like the American Cancer Society, Cancer Support Community, and CancerCare—to bring you Cancer.com.

Delivering Relevant Cancer Resources and Information...

Our mission is to provide patients and caregivers with up-to-date cancer resources and information. The goal is to help you feel educated, motivated, and inspired throughout your journey. We want to help you find what you need, when you need it.”