

Central NJ Multiple Myeloma Support Group – February 2018

Due to the inclement weather on Wednesday February 7, the support group meeting was cancelled. An email went to all members at 12:51 pm, advising of this cancellation. Due to a communication breakdown within Gmail, many of our members did not receive this email communication, especially those who utilize AOL. Gmail did not start sending delivery failures until Thursday, February 8. While we thought we had covered all the bases by posting a notice on Facebook, our web page, notifying Steeplechase and sending out this email, we now realize some of you may not have been aware of the cancellation. We apologize for any inconvenience this may have caused any of you. For the remainder of the winter, our group's web page will have a banner stating that any meeting cancellations will be displayed on the web page by 3:00 pm, the day of the meeting. Please be sure to check the website should you have any doubts as to whether our meeting is cancelled or not. Again, our web page address is

centralnj.support.myeloma.org

In December 2017, the American Society of Hematologists met in Atlanta for ASH 2017. After viewing many video recaps of this meeting, the following video by Dr. Durie of the IMF explains some of the information pertaining to multiple myeloma. You can view the video "Best of ASH 2017 - What patients and caregivers need to know", here...

www.myeloma.org/videos/best-ash-2017

COMMUNITY OUTREACH

As part of our continuing effort to reach out to as many multiple myeloma patients in our area as possible, I have recently sent notification of our support group meeting to the following. The first group all published our group meeting information on-line or in print...

- New Jersey Jewish News – Metro West
- New Jersey Jewish News – Middlesex
- NJ. Com
- Star Ledger

The next group were contacted, but no meeting information was found. I will contact them again regarding next month's meeting...

- New Jersey Hills Papers
- The Somerville Times
- My Papers On-Line
- My Central Jersey

We are in the process of correcting our group meeting information that is posted on RWJ's calendar of events. (Thank you Sheri Goldberg)

And finally, an email with our Support Group's flyer attached was sent to the following

- Veterans post 282 – Hackettstown
- Veterans post 2347 – Netcong

And these Veterans post will be contacted by phone, as there is no email listed

- Veterans post 2141 – Somerville
- Veterans post 1748 – Raritan

If anyone has any other community outreach ideas, please respond to this email.

UPCOMING MEETINGS

March 7, 2018

- Speaker Dr. Joshua Richter, Multiple Myeloma specialist, from the John Theurer Cancer Center, Hackensack New Jersey. (Thank you Diane Kranz)

April 4, 2018

- Speaker Nicole Rode, RN, BSN, OCN

Clinical Nurse Educator inVentiv Health for Janssen Oncology will present a program on Darzalex (Daratumumab).

May 2, 2018

- Celebration of Life Event

Briefly, our Celebration of Life Event is an evening for our support group members, their family and friends, and the group's invited guests to enjoy a catered dinner (free of charge), and celebrate life. This year we have received a grant from Celgene, financial support from Takeda for our refreshments, and I am waiting to hear if we will receive financial support from Janssen as well. Our Celebration used to be held in January, but we are experimenting with a Spring date this year. More information, plus an invitation will be sent in the upcoming months. If you are interested in helping out with this event, please respond to this email.

UPCOMING EVENTS

- Staten Island: Myeloma Support Group 3rd Annual Comedy Night
Sat, March 24, 2018 - 8:00pm Looney Bin Comedy Club

Looney Bin Comedy Club Presents Special Comedy Fundraiser for Staten Island Multiple Myeloma Support Group and International Myeloma Foundation with three top comics from around the country providing a night filled with laughter, all while benefiting a great cause.

<https://nightout.com/events/myelomasupportgroup/tickets>

In case you are in the area...

- 9th National Celebration - A Second Chance at Life...Survivor Symposium in Colorado. April 28th-29th 2018

“Who Should Attend?

Bone marrow, stem cell, cord blood transplant survivors.

Patients, spouses/partners and other family members of a transplant survivor.

Caregivers of a transplant survivor.

Healthcare professionals who work with transplant survivors.”

<https://www.bmtinfonet.org/9th-national-celebrating-second-chance-life-survivorship-symposium-2018>

INFORMATION

“New Test for Daratumumab Patients Help with M-Protein Accuracy”

<https://www.myelomacrowd.org/new-test-dara/>

“Diabetes Blood Tests for People of African, Mediterranean, or Southeast Asian Decent”

<https://www.niddk.nih.gov/health-information/diagnostic-tests/diabetes-blood-tests-african-mediterranean-southeast-asian>

Another helpful and informative site...

<https://myelomaresearchnews.com>

MARCH IS MYELOMA AWARENESS MONTH

Myeloma awareness is still a very important factor in fighting this disease. We are still hearing from patients at our group meetings who are misdiagnosed, or people who we meet who have no idea what myeloma is. The International Myeloma Foundation MAM (March is Myeloma Awareness Month) website will soon be available. You can help right now by just telling one person who does not know what myeloma is, about your journey, and also help make others aware of our group. Attached is an on-line completable form from the IMF (please download the form first, so that it may be completed) regarding our MM physicians and our primary care physicians.

“The International Myeloma Working Group’s (IMWG) guidelines are improving outcomes for patients around the world. The IMF would like to provide those guidelines to your medical team. Please share your doctors’ contact information with us and we will make sure that they are sent the most current treatment guidelines for free.”

Please take a few minutes to complete this form and send it back to the IMF, via email, fax, or print and bring it to the next meeting.

Patient Power

<https://www.patientpower.info/multiple-myeloma>

I received an email from the leader of the Staten Island support group, and former member of our group, Laura Mooney from Cynthia Chmielewski...

“I'm doing some part time work with [PatientPower.info](https://www.patientpower.info). In honor of Blood Cancer Awareness Month Patient Power is seeking individuals ... to record a brief interview to shed light on what matters most when it comes to treating and living with myeloma. It will be a conversation between two people. (you and a caregiver, you and a doctor, you and a friend).”

Here is a link of some interviews that have already been recorded

<https://www.bloodcounts.com>

and where to add your own myeloma story...

<https://www.bloodcounts.com/stories/>

Hope to see many of you at our March meeting. Stay healthy, warm, and safe as this winter continues on. Till then,

Debbie Morelli

