

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP SEPTEMBER 5, 2018 MEETING RECAP

At our September 5, 2018 support group meeting we were fortunate to have Robin and Michael Tuohy as our guest speakers. Robin is the Senior Director of Support Groups for the International Myeloma Foundation, and wife and caregiver to her husband, Michael Tuohy, an 18-year Multiple Myeloma survivor.

Robin and Michael presented an interesting and compassionate recap of their personal myeloma journey, while also presenting multiple myeloma information to the group. You can hear Robin and Michael's story at "Myeloma Voices" www.myeloma.org/videos/michael-and-robin-tuohy

Here are a few interesting multiple myeloma updates from the evening...

- Mass Spec Blood Test – a more sensitive blood test to check for Minimal Residual Disease (MRD) in a myeloma patient. Mass Spec can find 1 myeloma cell in 10 million cells.
- From GlaxoSmithKline, GSK2857916, an investigational anti-B-cell maturation antigen (BCMA) antibody-drug conjugate for treatment of multiple myeloma. www.gsk.com/en-gb/media/press-releases/gsk-presents-promising-new-data-for-priority-bcma-asset-from-its-emerging-oncology-pipeline-at-59th-ash-meeting/
- Venetoclax – "Venetoclax monotherapy showed activity among patients with relapsed or refractory multiple myeloma, particularly those with t(11;14)" www.healio.com/hematology-oncology/myeloma/news/in-the-journals/%7B1bf4402a-b839-4d3a-a032-51fc58356009%7D/venetoclax-demonstrates-activity-in-multiple-myeloma
- "Freelite™ test". "This test helps determine low level of abnormal free light chain and has been accepted as the new tool for diagnosis of non-secretory multiple myeloma."

We also welcomed two new members to our group.

Below are some upcoming events that may be of interest to you...

The MMRF is sponsoring two free webinars on the following topics:

- Evaluating Treatment Options for Relapsed/Refractory Patients Evaluating Treatment Options for Relapsed/Refractory Patients

To View Slides...

https://drive.google.com/file/d/1h5ll_fgj6vn8N7jmufgfjdbv6tmv_ez0/view

To View Video

https://www.youtube.com/watch?v=1M9A_Hq-eGI&feature=youtu.be

- Caregivers: An Essential Part Of the Myeloma Care Team

Oct 24 @1:00 pm

https://beacon360.content.online/xbcs/S1531/catalog/product.xhtml?eid=8955&_ga=2.38285859.1410604462.1536703055-799127737.1505002384&_gac=1.212019744.1536704200.EAlalQobChMIk6bPkf2z3QIVml7ICh0qwwkOEAAAYASAAEgJ-CPD_BwE

September 22, 2018 – Clark, NJ

6th Annual Miracles for Myeloma 5K Race/Walk

<http://give.myeloma.org/miracles2018>

Please visit the website to sign up (please designate “Central Jersey Memorial Team”), donate, or purchase a Remembrance Path Placard, in memory of, or to honor someone with Multiple Myeloma or another cancer. Raffle tickets for the beautiful, homemade, “Miracles for Myeloma Quilt” are still available for \$5, and will also be available on race day. Winner need not be present at the time of the drawing on race day.

OCTOBER 7, 2018 - Washington DC

MMRF 5K Walk/Run

<https://walkrun.themmrf.org/washingtondc18>

October 12-13 2018 - Philadelphia, Pa

International Myeloma Foundation Patient/Family Seminar

<http://www.cvent.com/events/2018-imf-philadelphia-patient-family-seminar/event-summary-2de04d1a77a24853a769d448126c41f3.aspx?ct=8219faf0-1e56-47f4-89a0-260b9bc84eab>

OCTOBER 20, 2018 - New York City

MMRF 5K Walk/Run

<https://walkrun.themmrf.org/newyorkcity18>

NOVEMBER 10, 2018 – Philadelphia

MMRF 5K Walk/Run

<https://walkrun.themmrf.org/philadelphia18>

And some information that may be of interest to you...

A New Way to Support the IMF (At No Cost to You!)

“The Charity Charge World MasterCard earns you 1% cash back on every purchase and turns that cash back into an automatic donation to the IMF.

Some of the benefits include:

- No annual fee

- Low-interest rates and Premium World MasterCard benefits
- Tax-deductible donations

Even if you use your Charity Charge card just to buy your daily coffee or weekly groceries, these automatic donations add up in a big way! Charity Charge will also underwrite the donation processing fees so that the IMF receives your full donation. When you add this card to your wallet, the IMF will earn critical funding for our programs that serve myeloma patients, family members, and the medical community.”

www.charitycharge.com/ein/?npoKeyword=95-4296919

From the International Myeloma Foundation... www.myeloma.org

HOW TO CREATE IMF FUNDRAISERS ON FACEBOOK

www.myeloma.org/article/how-create-imf-fundraisers-facebook

IF A MYELOMA PATIENT HAS MRD-NEGATIVE STATUS, DOES THAT MEAN THAT PATIENT IS CURED?

www.myeloma.org/videos/if-myeloma-patient-has-mrd-negative-status-does-mean-patient-cured-0

Myeloma Voices - An Interview with Deborah and Frank Morelli at SGLS in Dallas, TX

www.myeloma.org/videos/debra-and-frank-morelli

WHY PREVENTION MATTERS

www.myeloma.org/why-prevention-matters

ROLE OF RESILIENCE IN MYELOMA

www.myeloma.org/role-resilience-myeloma

PRECISE VS. PERSONAL MYELOMA TREATMENT

www.myeloma.org/precise-vs-personal-myeloma-treatment

Myeloma Updates 2018: Best of ASCO/EHA/IMWG

www.myeloma.org/videos/myeloma-updates-2018-best-ascoehaimwg

From Myeloma Research News...

<https://myelomaresearchnews.com/>

Visit their website to view the following articles...

1. Combining Simple Blood Tests Might Accelerate Diagnosis of Myeloma
2. Revlimid-based Therapies are Best Maintenance Option for Newly-diagnosed Multiple Myeloma Patients, Analysis Finds
3. Some with Smoldering Multiple Myeloma May Benefit from Immediate Treatment, Study Suggests
4. FDA Grants Priority Review to Empliciti Combo Therapy for Relapsed or Refractory Myeloma
5. Amgen Seeks Expanded Approval of Kyprolis to Once-weekly Regimen for Relapsed Myeloma
6. BL-8040 Speeds Collection of Stem Cells for Transplant in Myeloma Patients, Phase 3 Data Suggest
7. Surface Oncology's SRF231 Granted Orphan Drug Status for Treatment of Multiple Myeloma
8. CHMP Recommends Darzalex Combo Therapy for Certain Newly Diagnosed Multiple Myeloma Patients
9. Machine-learning Algorithm Predicts Responses to Myeloma Treatments
10. Urine Tests May Be Better Than Serum for Multiple Myeloma Screening, Study Suggests

11. Karyopharm Seeks Selinexor's Accelerated Approval in US for Heavily Treated Myeloma Patients
12. Ninlaro Could Replace First-line Velcade in Older Myeloma Patients, Study Suggests
13. Dendritic Cell Vaccine in Immunotherapy Triple Combo Seen to Boost Immune Response to Myeloma in Early Study

Other News...

NEW MYELOMA RESEARCH PROJECT FOLLOWS IN THE FOOTSTEPS OF ISTOPMM TO STUDY MYELOMA PRECURSORS

www.myeloma.org/blog/dr-duries/new-myeloma-research-project-follows-footsteps-istopmm-study-myeloma-precursors-0

DID YOU KNOW?

“Did you know that black men and women are diagnosed with myeloma at approximately twice the rate as the combined average for all ethnic backgrounds? Unfortunately, we don't yet know the reasons for these rates. The African American community needs access to resources to better recognize symptoms, understand their diagnosis, and research treatment options for this disease. That's why the International Myeloma Foundation has launched a mailing list at diversity.myeloma.org. Sign up so that you can be the first to know of any new developments, studies, or programs that may affect you and your loved ones in the African American community.” Also, visit their website for more information.

www.myeloma.org/diversity-multiple-myeloma

NEW MYELOMA RESEARCH PROJECT FOLLOWS IN THE FOOTSTEPS OF ISTOPMM TO STUDY MYELOMA PRECURSORS

“The target population for the survey includes people with first-degree relatives who have had multiple myeloma, and African-Americans, since African-Americans are three times more likely than whites to develop the precursor conditions and tend to develop them at an earlier age.”

www.myeloma.org/blog/dr-duries/new-myeloma-research-project-follows-footsteps-istopmm-study-myeloma-precursors-0

OTHER WEB RESOURCES...

Follow “Multiple Myeloma” on Twitter

- ASCO Twitter feed

<https://twitter.com/asco?lang=en>

- ASH Twitter feed

https://twitter.com/ash_hematology?lang=en

- Myeloma Crowd

<https://myelomacrowd.org/>

- Myeloma Crowd Radio

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

For our October 3, 2018 meeting, we will have guest speaker Scott Friedly, from Takeda, who spoke to the group last year on insurance. We look forward to hearing from Scott again. Please remember, that you can access all previous recaps on the CNJMMSG website, centralnj.support.myeloma.org

Hope to see many of you in October. Stay well...

Debbie Morelli