

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MAY 2018 RECAP

Our Celebration of Life Event, which is usually held in January, was held on May 2, 2018 this year. This was an excellent decision!! The evening was definitely spring-like, and our Celebration room looked beautiful with the pastel colored table cloths and Spring flowers on each table. The food was catered again this year and paid for with a grant from Celgene and monetary support from Takeda. We also received a gift card from Whole Foods in Bridgewater, which was used to purchase our wraps. Frank began the evening with a very warm and heartfelt greeting, reminding us all that in spite of this disease, we are miraculous in the support we give our families and each other, and the support we all receive in return. Here is my take on the evening as well...

CELEBRATION OF LIFE

For our members who are newly diagnosed with MM, MGUS, or Smoldering MM to those diagnosed 3 years ago...

We Celebrate with you. We Celebrate that you have found and joined our Support Group, we Celebrate that you are educating yourselves about MM.

For members who were diagnosed 3-7 years ago...

We Celebrate with you. We Celebrate that you have joined our Support Group as well, we Celebrate that you have returned to your daily routines, though they may now be new routines, we Celebrate that you are able to experience the availability of all the new therapies that have been approved for MM in the last few years.

For our members who were diagnosed 7-10 plus years ago

We Celebrate with you. We Celebrate that you have joined our Support Group...some of you had been with Paula since the group's beginning, we Celebrate that you have been able to experience the availability of all the new approved therapies in MM that are now available, when at the time you were

diagnosed there were only a handful. We Celebrate you. You are our inspiration, you are our hope.

Fifty of our members, families, and invited guests were in attendance, which included three new members! (We all hope to see you again in June). Thank you again to the Steering Committee members who helped to make this Event a success. We hope many more of you will join us next year in May for our Spring Celebration of Life Event!

And now important dates and information...

May 9, 2018

Staten Island

The Staten Island Multiple Myeloma Support Group will be meeting at the Hilton Garden Inn next week in the Cherry Willow Suite at 7:00 PM. This special meeting will be hosted by the law firm of Barasch and McGarry from Manhattan to help register patients who have been diagnosed with one of the 68 designated diseases (including Multiple Myeloma) resulting from exposure to toxic dust following the 9/11 terrorist attack.

Benefits and funds may be available so if you or someone you know falls into this category, please let them know about this meeting. The attorneys will be available to answer questions that evening.

For questions or more information, please contact Laura Mooney at 917-715-9665, or visit their website, www.statenisland.myeloma.org

Here is some more information on that subject from Dr. Durie...

THE TRUTH ABOUT TOXINS: NEW STUDIES POINT TO INCREASED RISK OF MGUS IN FIREFIGHTERS EXPOSED TO 9/11 CARCINOGENS

WRITTEN BY: BRIAN GM DURIE MD

www.myeloma.org/blog/dr-duries/truth-about-toxins-new-studies-point-increased-risk-mgus-firefighters-exposed-911

May 19, 2018

Lakewood, NJ

Takeda Oncology presents a Ninlaro presentation featuring Dr. David Siegel, M.D., from John Theurer Cancer Center at HUMC & a Patient Ambassador

<https://www.ninlaro.com/events>

September 22, 2018

Clark, NJ

Miracles for Myeloma 6th Annual 5K Walk/Run. This event is organized and run by our members Ron and Sheree Pask along with Gina Guarino. It is not to soon to register!

http://give.myeloma.org/site/TR?fr_id=1560&pg=entry#.Wu3Gdogvw2w

ASK DR. DURIE VIDEOS

Options for myeloma patients who have undergone Darzalex (Daratumumab) therapy and relapsed.

<https://www.myeloma.org/videos/options-myeloma-patients-who-have-undergone-darzalex-daratumumab-therapy-and-relapsed>

Should myeloma patients stay on maintenance for several years?

<https://www.myeloma.org/videos/should-myeloma-patients-stay-maintenance-therapy-several-years-0>

When should a myeloma patient begin treatment?

<https://www.myeloma.org/videos/when-should-myeloma-patient-begin-treatment-0>

What does it mean for myeloma patients if their freelite test results show antigen-excess?

<https://www.myeloma.org/videos/what-does-it-mean-myeloma-patients-if-their-freelite-test-results-show-antigen-excess-0>

What is the best diet for multiple myeloma patients?

www.myeloma.org/videos/what-best-diet-myeloma-patients-0

DR. DURIE'S BLOG

April 5: Toxic exposures unleashed!

www.myeloma.org/blog/dr-duries/toxic-exposures-unleashed

April 12: Black Swan researchers identify good-risk and poor-risk MRD patients, China's 'disruptive' biotech, and reasons to eat 'real food'.

<https://www.myeloma.org/blog/dr-duries/black-swan-researchers-identify-good-risk-and-poor-risk-mrd-patients-china%E2%80%99s->

April 26: A new myeloma research project follows in the footsteps of iStopMM to study myeloma precursors. [Stand Up to Cancer \(SU2C\)](#) recently awarded \$10 million to a SU2C Dream Team that wants to move the treatment of multiple myeloma from a "watch and wait" approach to early detection of precursor conditions before they turn into fully developed disease. The target population for the survey includes people over the age of 45 with first-degree relatives with myeloma and African-Americans, since studies show that African-Americans are three times more likely to develop these precursor conditions than white Americans, and also to develop them at an earlier age. **Our support group will be involved in this development in the near future!**

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

More information

www.myelomaresearchnews.com/2018/05/04/new-multiple-myeloma-approach-focuses-precursor-conditions/

April 12: Selinexor receives fast track designation from FDA for the treatment of Patients with penta-refractory Multiple Myeloma.

<https://globenewswire.com/news-release/2018/04/10/1467614/0/en/Karyopharm-s-Selinexor-Receives-Fast-Track-Designation-fromFDA-for-the-Treatment-of-Patients-with-Penta-Refractory-Multiple-Myeloma.html>

From THE MYELOMA BEACON

Faster Darzalex Infusions Can Be Safe

<http://www.myelomabeacon.com/news/2018/04/30/shorter-darzalex-infusion-times/>

Gradual Response To Initial Treatment May Be Sign Of Better Prognosis In Multiple Myeloma

<http://www.myelomabeacon.com/news/2018/04/23/speed-of-response-and-multiple-myeloma-survival/>

From MYELOMA RESEARCH NEWS

Chip-based Blood Test Might Replace Bone Marrow Biopsies for Myeloma, Scientists Say

www.myelomaresearchnews.com/2018/05/02/chip-based-blood-test-myeloma-might-replace-bone-marrow-biopsy/

New Method of Classifying Malignant Myeloma Cells Improves Outcomes, Study Finds

www.myelomaresearchnews.com/2018/04/23/new-method-classifying-malignant-myeloma-cells-improved-outcomes/

P-BCMA-101 Shows Early Effectiveness in First Multiple Myeloma Patients Treated in Phase 1 Trial

www.myelomaresearchnews.com/2018/04/20/p-bcma-101-effective-safe-multiple-myeloma-patients-phase-1-trial/

Selinexor Gains FDA Fast Track Designation for Refractory Multiple Myeloma Patients

www.myelomaresearchnews.com/2018/04/13/selinexor-hits-fda-fast-track-for-refractory-multiple-myeloma-patients/

Screening for Multiple Myeloma Precursor Could Cut Deaths from the Cancer, Study Finds

www.myelomaresearchnews.com/2018/04/16/multiple-myeloma-precursor-screening-could-cut-deaths-from-the-cancer/

FROM THE MMRF (Multiple Myeloma Research Foundation

<https://www.themmrp.org/>)

Multiple Myeloma Research Foundation Awards \$7 Million to Accelerate Precision Immunotherapies for Myeloma Patients

<https://www.themmrp.org/research-partners/mmrp-learning-network/mmrp-immunotherapy-initiative/>

Dr. Biran, Multiple Myeloma Specialist from Hackensack, NJ, will be joining us as our guest speaker on June 6, 2018. Hope to see you at our next meeting.

Stay well,

Debbie Morelli