

## CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP

### AUGUST 1, 2018 MEETING RECAP

This was an open meeting. Rather than have a member “roundtable”, we participated in a “toilet paper” roundtable! Each person took the appropriate number of toilet paper sheets they thought they would need, when actually they were used to tell the group facts about themselves we may not have known. The more sheets, the more we learned about each of us.

I also shared with the group two newspaper articles, a small one from December 8, 2013, found in the middle section of the Star Ledger, about this little 8-year-old girl, Emily Whitehead, who suffered from lymphoblastic leukemia and had no other options. She received experimental gene therapy two years prior, and was still cancer free. The other article, from July 13, 2017, front page of the “Health” section in the Star Ledger, was another article about Emily Whitehead, who was still cancer free. Her treatment...CAR T-cell therapy. And, now in 2018, we have CAR T-cell therapy in trials for Multiple Myeloma. Good news indeed!

Here are some events that may be of interest to you...

#### **August 18, 2018 - Myeloma Crowd Radio**

Jenny Ahlstrom, founder of the Myeloma Crowd, will be in Somerville, NJ on Saturday, August 18th for a multiple myeloma workshop sharing a new product called HealthTree. HealthTree was created for myeloma patients by myeloma patients to help accelerate a cure. HealthTree is free for patients.

With HealthTree you can:

- Find personally relevant myeloma treatment options and clinical trials
- Track your key myeloma lab markers over time
- Answer myeloma researcher survey questions to help them come to faster conclusions
- View reports on group data like patient outcomes after certain treatments or the impact of maintenance therapy on remission durations
- Find a myeloma specialist
- Work in collaboration with other patients, myeloma researchers and doctors to deliver the right treatment to the right patient at the right time for our very best personalized care.

Bring your laptop and join them for a hands-on workshop where they provide one-on-one help using HealthTree. If you don't have a laptop, they will have several Chromebooks you can use. Food will be provided.

Date: Saturday, August 18, 2018

Place: The Salad House of Somerville, [58 West Main Street #2216, Somerville, NJ 08876](#)

Time: 10:00 am - Noon

To attend, please RSVP here so they can plan for food: <https://meetups.myelomacrowd.org/events/details/crowdcare-somerville-presents-healthtree-workshop-find-your-best-myeloma-treatment-options-and-help-accelerate-a-myeloma-cure#/>

To create a HealthTree account (please write down your username and password), register here: [www.healthtree.org](http://www.healthtree.org)

**August 15, 2018 - 1:00PM EST**

Webinar 3: Myeloma Vaccines

Presenting Faculty:

David Avigan, MD, Dana Farber Cancer Institute

Nina Shah, MD, University of California, San Francisco

REGISTER TODAY

AT:<https://beacon360.content.online/xbcs/S1531/catalog/product.xhtml?eid=8376>

**SEPTEMBER 22, 2018**

Miracles for Myeloma 5K Run/Walk

Now is the time to register for the Miracles for Myeloma 5K Run/Walk which will be held on the morning of Saturday, September 22<sup>nd</sup> at Oak Ridge Park in Clark, NJ, the same location as prior years. For those of you who are ready to join our team as a runner, or as a walker, or to make a donation, just go to <http://give.myeloma.org/miracles2018>. Be sure to indicate that you want to join the Central Jersey Memorial Team.

This year one of our members, Mary, is busy working on a hand-made quilt to be raffled off at the Miracles for Myeloma 5K. The quilt will be approximately 46" x 62" with a color of maroon and white for myeloma. It will also have the Miracles for Myeloma name and logo displayed in the middle. Raffle tickets are \$5.00 and you do not need be present at the race to participate.

Contact [miracles4mm@comcast.net](mailto:miracles4mm@comcast.net) for information.

## **MMRF TEAM FOR CURES**

“Since 2001, this family friendly 5K walk/run program has raised both awareness and funds for multiple myeloma research. Today, the series is held annually in thirteen cities and participation offers camaraderie and knowledge sharing for patients, patient family members and friends, members of the myeloma community, and others. JOIN UP! TEAM UP! SHOW UP! Be a part of the team that cures multiple myeloma, once and for all!”

**October 7, 2018 – National Harbor, MD**

[www.nationalharbor.com/event/7am-mmrf-5k-walkrun-2/](http://www.nationalharbor.com/event/7am-mmrf-5k-walkrun-2/)

**October 20, 2018 – Hudson River Park, NYC**

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

**November 10, 2018 – Fairmont Park, Philadelphia Pa**

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

And some important information...

**Karyopharm Seeks Selinexor’s Accelerated Approval in US for Heavily Treated Myeloma Patients**

[https://myelomaresearchnews.com/2018/07/27/karyopharm-seeks-fda-accelerated-approval-selinexor-myeloma/?utm\\_source=Myeloma+List&utm\\_campaign=1f2b77ca51R](https://myelomaresearchnews.com/2018/07/27/karyopharm-seeks-fda-accelerated-approval-selinexor-myeloma/?utm_source=Myeloma+List&utm_campaign=1f2b77ca51R)

[SS WEEKLY EMAIL CAMPAIGN&utm\\_medium=email&utm\\_term=0\\_14fcd0022a-1f2b77ca51-72846797](https://myelomaresearchnews.com/2018/07/25/older-multiple-myeloma-patients-ninlaro-could-replace-first-line-velcade/?utm_source=Myeloma+List&utm_campaign=1f2b77ca51-RSS_WEEKLY_EMAIL_CAMPAIGN&utm_medium=email&utm_term=0_14fcd0022a-1f2b77ca51-72846797)

**Ninlaro Could Replace First-line Velcade in Older Myeloma Patients, Study Suggests**

[https://myelomaresearchnews.com/2018/07/25/older-multiple-myeloma-patients-ninlaro-could-replace-first-line-velcade/?utm\\_source=Myeloma+List&utm\\_campaign=1f2b77ca51-RSS WEEKLY EMAIL CAMPAIGN&utm\\_medium=email&utm\\_term=0\\_14fcd0022a-1f2b77ca51-72846797](https://myelomaresearchnews.com/2018/07/25/older-multiple-myeloma-patients-ninlaro-could-replace-first-line-velcade/?utm_source=Myeloma+List&utm_campaign=1f2b77ca51-RSS_WEEKLY_EMAIL_CAMPAIGN&utm_medium=email&utm_term=0_14fcd0022a-1f2b77ca51-72846797)

**FRESH—AND HEALTHY—FOOD CHOICES FOR THE SUMMER**

**WRITTEN BY: BRIAN GM DURIE MD**

[www.myeloma.org/blog/dr-duries/fresh-and-healthy-food-choices-summer](http://www.myeloma.org/blog/dr-duries/fresh-and-healthy-food-choices-summer)

And some information you may find helpful...

**WHAT ARE THE IMMEDIATE AND LONG-TERM SIDE EFFECTS OF AN AUTOLOGOUS STEM CELL TRANSPLANT (ASCT)?**

[www.myeloma.org/videos/what-are-immediate-and-long-term-side-effects-autologous-stem-cell-transplant-asct-0](http://www.myeloma.org/videos/what-are-immediate-and-long-term-side-effects-autologous-stem-cell-transplant-asct-0)

## **A VERY SPECIAL WEDDING MARKS A HIGH POINT IN ONE FAMILY'S REMARKABLE MYELOMA JOURNEY**

**WRITTEN BY: BRIAN GM DURIE MD**

<https://www.myeloma.org/blog/dr-duries/very-special-wedding-marks-high-point-one-family%E2%80%99s-remarkable-myeloma-journey>

## **10 REASONS TO JOIN A SUPPORT GROUP**

[www.myeloma.org/article/10-reasons-join-support-group](http://www.myeloma.org/article/10-reasons-join-support-group)

## **10 REASONS TO ATTEND AN IMF EDUCATIONAL OUTREACH EVENT**

[www.myeloma.org/article/10-reasons-attend-imf-educational-outreach-event](http://www.myeloma.org/article/10-reasons-attend-imf-educational-outreach-event)

## **Tips on How to Get and Use Your Health Insurance**

[www.bmtinfonet.org/video/tips-how-get-and-use-your-health-insurance](http://www.bmtinfonet.org/video/tips-how-get-and-use-your-health-insurance)

## **Your Eyes and Chronic Graft-versus-Host Disease**

[www.bmtinfonet.org/video/your-eyes-and-chronic-graft-versus-host-disease](http://www.bmtinfonet.org/video/your-eyes-and-chronic-graft-versus-host-disease)

## **CLINICAL TRIAL FACT SHEETS**

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

## **Firefighter Cancer Registry Act Signed into Law**

**President Trump signed H.R. 931, the Firefighter Cancer Registry Act of 2017 into law on July 9, 2018. This new law will help researchers better understand cancer in firefighters. It creates a voluntary national registry to collect information about cancer incidence in firefighters.**

**[www.congress.gov/bill/115th-congress/house-bill/931/text?q=%7B%22search%3A%5B%22HR+931%22%5D%7D&r=1](http://www.congress.gov/bill/115th-congress/house-bill/931/text?q=%7B%22search%3A%5B%22HR+931%22%5D%7D&r=1)**

## **MYELOMA UPDATES 2018: BEST OF ASCO/EHA/IMWG**

**[www.myeloma.org/videos/myeloma-updates-2018-best-ascoscoehaimwg](http://www.myeloma.org/videos/myeloma-updates-2018-best-ascoscoehaimwg)**

**CAN KYPROLIS® (CARFILZOMIB) BE ADMINISTERED ONCE A WEEK, RATHER THAN TWICE A WEEK?**

**[www.myeloma.org/videos/can-kyprolis-carfilzomib-be-administered-once-week-rather-twice-week-0](http://www.myeloma.org/videos/can-kyprolis-carfilzomib-be-administered-once-week-rather-twice-week-0)**

## **MYELOMA MATRIX 2.0: SMART SEARCH**

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

## **ONLINE INFORMATION RESOURCES**

[Drug Reimbursement Information and Assistance](#)

[Housing and Travel Assistance](#)

[Pain Management](#)

[Legal](#)

[Counseling and Support](#)

[Transplant](#)

[International Organizations](#)

[Government](#)

[www.myeloma.org/understanding/online-information-resources](http://www.myeloma.org/understanding/online-information-resources)

**Reflections Ambassador Program – Celgene Corporation**

**“Your Multiple Myeloma Story Can Make a Difference”**

[www.facebook.com/Celgene/photos/interested-in-sharing-your-experience-with-multiple-myeloma-learn-more-about-the/759738487513626/](https://www.facebook.com/Celgene/photos/interested-in-sharing-your-experience-with-multiple-myeloma-learn-more-about-the/759738487513626/)

## **RIDE TO TREATMENT**

The American Cancer Society ([www.cancer.org](http://www.cancer.org)) has a “Road to Recovery Program”. They will find a volunteer in your area to drive you to your treatment should you need a ride. They are now partnering with the car service LYFT. If there are no volunteers in your area to



drive you LYFT will provide the transportation to your treatment free of charge. Contact the American Cancer Society for more information.

Our next meeting will be held on September 5, 2018 from 6:30-8:30 pm and our special guests will be Robin Tuohy, Senior Director Support Groups, for the International Myeloma Foundation, and her husband Michael Tuohy, myeloma patient/survivor. Due to expected large turnout, we will be meeting in the 3<sup>rd</sup> floor conference room of Steeplechase instead of our usual location. Mark your calendars to come and hear the story of Michael's MM journey and Robin's journey as MM patient's caregiver. There will be time for Q/A.

Till then, stay well, cool, and INFORMED!!

Debbie Morelli