

## CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP

### MAY 6, 2021 VIRTUAL MEETING RECAP

The Central NJ MM Support Group met virtually on May 6, 2021 and there were 31 members in attendance.

**Guest Speaker:** Suzy Graham, RN Oncology/Nurse Liaison at Karyopharm Therapeutics

**Topic:** Understanding Lab Values in Multiple Myeloma

**News:** A new virtual support group has been created for Myeloma patients with young children...**Virtual Multiple Myeloma Support Group For Families With Young Children.** For the purpose of this support group, young children are defined as “living at home and High School age and younger”.

This group will meet the 2<sup>nd</sup> Tuesday of the month from 12:00-1:00pm EDT.

Their website can be found at [www.myeloma.org/support-group/mm-families](http://www.myeloma.org/support-group/mm-families) and their email address is [MMfamilies@imfsupport.org](mailto:MMfamilies@imfsupport.org)

**Saturday May 15, 2021 1:00-3:00 pm**

**Delmarva Multiple Myeloma Support & Networking Group (Delaware)**

- **Physical education coach, Mary Bruno, from the Livestrong program will be presenting a program on the importance of exercise and an overview of the Livestrong Program.**

- **To join this virtual meeting please contact Susan Iwahashi at [myelomaemailsue@gmail.com](mailto:myelomaemailsue@gmail.com) or 302-569-2775 to be invited.**

### **Miracles for Myeloma Virtual 5K Run/Walk**

- Ron and Sheree Pask provided an update on the grant presentation to Dr. Eugenio Morelli of the Dana-Farber Cancer Institute, who was the recipient of the Brian D. Novis Research Grant, as a result of the monies raised at the 2020 Virtual Miracles for Myeloma 5k Run/Walk. Miracles was the only fundraising group to raise enough money to fund a Brian D. Novis Research Grant in 2020!
- Miracles 2021 will be held virtually again this year on September 18, 2021. Soon the Miracles website will be available for this year's race registration.
- To view an article on the grant presentation to Dr. Morelli and his research information, go to <https://www.myeloma.org/resource-library/myeloma-today-winter-2021>

### **IMPORTANT !!**

- Dr. Durie presented a program to the IMF Support Group Leaders  
“Update on Vaccines and COVID 19”
- Link to the replay of the Zoom meeting:
  - [https://www.dropbox.com/s/8p60c5cjwgigqg5/zoom\\_0.mp4?dl=0](https://www.dropbox.com/s/8p60c5cjwgigqg5/zoom_0.mp4?dl=0)

- This presentation was very informative and Dr. Durie gave his medical opinion on what Myeloma patients should and should not do if they are vaccinated.

### **From Twitter:**

- Dr. Martin: Improving Survival Rates in High-Risk Multiple Myeloma
  - <https://www.docwirenews.com/condition-center/multiple-myeloma-knowledge-hub/multiple-myeloma-kol-video/dr-martin-improving-survival-rates-in-high-risk-multiple-myeloma/>
- “Emily Whitehead, CAR T-cell pioneer and the first pediatric ALL CAR T19 patient, now 9 years out from her infusion followed by sustained CR initially documented 23 days later. Much of what we know about CAR T-cell CRS management we learned from her.”
  - <https://twitter.com/GruppSteve/status/1391873717572153352>
  - We have discussed Emily’s CAR T-cell journey a few times at our meetings, especially each time a news update on her broke. Emily was a child with ALL, ( Acute Lymphocytic Leukemia ) with no other treatment options left. CAR T-cell was a new experiment treatment at the time at UPenn and her family opted to give it a try. She is now nine years cancer free, and we now have CAR t-cell therapy approved for MM. Thank you, Emily.

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### INFORMATIONAL MYELOMA LINKS

#### International Myeloma Foundation

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

- Webinar on How to Optimize and Protect your Immune System: A Nutrition Approach
  - <https://www.myeloma.org/videos/webinar-how-optimize-protect-your-immune-system-nutrition-approach>
    - REPLAY AND SLIDES
- International Myeloma Foundation Says FDA Approval of Bristol Myers Squibb's and bluebird bio's CAR T-Cell Immunotherapy Treatment for Multiple Myeloma Is Welcome News for Patients
  - <https://www.myeloma.org/fda-approval-abecma-idecabtagene-vicleucel>
- Virtual Webinar on How The Future is Looking Bright for Myeloma Patients
  - <https://www.myeloma.org/videos/patient-family-webinar-future-looking-bright-myeloma-patients>
    - REPLAY AND SLIDES
- Patience and Progress in the Search for a Cure
  - <https://www.myeloma.org/blog/patience-progress-search-cure>
- Using the Immune System to Fight Multiple Myeloma

- <https://www.myeloma.org/videos/using-immune-system-fight-multiple-myeloma>
- #AskDrDurie
  - How does the M-spike correlate to the amount of myeloma protein in the body?
- IMF Infoline
  - 1-800-452-2873 or [infoline@myeloma.org](mailto:infoline@myeloma.org)
    - Due to COVID please leave a message
- A Day in the Life Podcast: Jack Aiello
  - <https://www.myeloma.org/audio/day-life-podcast-jack-aiello>
    - Listen to Jack Aiello, 26 year MM survivor

## **Veterans Against Myeloma**

<https://veterans.myeloma.org/about-us/>

## **Multiple Myeloma Research Foundation**

<https://themmrf.org/>

- MyDRUG Trial Preliminary Results Discussed at ESH Meeting
  - <https://themmrf.org/2021/04/16/mydrug-trial-preliminary-results-discussed-at-esh-meeting/>
- 4/10/21 Patient Summit – Top FAQs
  - <https://themmrf.org/2021/04/12/4-10-21-patient-summit-top-faqs/>

- Resources
  - <https://themmrf.org/resources/>

## Myeloma Crowd

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

- **Getting to Know the Abecma (ide-cel) CAR T Therapy**
  - **May 18 @ 12:00pm — 1:00pm EDT**
  - **Register - [https://www.myelomacrowd.org/event/getting-to-know-the-car-t-therapy-what-is-it-really-like-/](https://www.myelomacrowd.org/event/getting-to-know-the-car-t-therapy-what-is-it-really-like/)**
- FDA Grants RMAT Designation for Donor CAR T Therapy Allo-715 for Relapsed Myeloma
- **Isatuximab Now FDA Approved with Kyprolis and Dex for Relapsed/Refractory Myeloma!**
- MC Community Event: Maneuvering the Workplace When You Have Cancer (video)
- MC Community Event: A New Drug for Relapsed/Refractory Myeloma Patients: Melflufen(video)
- HealthTree University
  - HealthTree University: Imaging in Myeloma (Part 3 of 3)

## Myeloma Crowd Radio

<https://www.myelomacrowd.org/myeloma-crowd-radio-episodes/>

- Full Show: The New Abecma (ide-cel) CAR T FDA Approval in Multiple Myeloma with Dr. Noopur Raje, Mass General

## **HealthTree University (YouTube)**

<https://www.youtube.com/channel/UC27i8v856WBGy-4ONPJS0MQ>

## **Myeloma Beacon**

<https://myelomabeacon.org/>

## **Myeloma Central**

<https://www.myelomacentral.com/>

- Standing in the Gaap
  - <https://www.myelomacentral.com/multiple-myeloma-african-americans/what-is-standing-in-the-gaap/>

## **Cure**

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

- FDA's Abecma Approval a 'Great Blessing' for Patients with Multiple Myeloma
- Progression-Free Survival and Minimal Residual Disease Negativity May Result From Combination Therapy in Newly Diagnosed Multiple Myeloma
- Triple Therapy Shows Promise for Elderly, Frail Patients With Previously Treated Multiple Myeloma

## **CureTalks**

<https://www.curetalks.com/category/myeloma/>

- UltraCAR-T Therapy – Scope & Possibilities in Multiple Myeloma Management
  - Live Talk on May 17, 2021, 10:00 am EST
  - <https://www.curetalks.com/ultracar-t-therapy-scope-possibilities-in-multiple-myeloma-management/>

## **Onclive/Onclive Videos**

<https://www.onclive.com/clinical/multiple-myeloma>

- Quadruplet Regimens Revolutionize Frontline Myeloma Treatment
  - <https://www.onclive.com/view/quadruplet-regimens-revolutionize-frontline-myeloma-treatment>
- Daratumumab-Based Triplets Translate to Improved MRD-Negative Remissions in Myeloma
- Dr. Diamond on the Rationale for Examining Long-Term MRD in Myeloma
- Novel Triplets Shed New Light on Sequencing in Relapsed/Refractory Myeloma
- Motixafortide/G-CSF Results in 4.9-Fold Increase in Achieving Target Stem-Cell Mobilization for Transplant in Myeloma
- Clinical Trial Diversity Efforts Gain Steam
- Dr. Vij on the Integration of Selinexor in Relapsed/Refractory Multiple Myeloma



- <https://www.onclive.com/view/dr-vij-on-the-integration-of-selinexor-in-relapsed-refractory-multiple-myeloma>

- Plus, more!

## **Myeloma Research News**

<https://myelomaresearchnews.com/>

## **Myeloma Hub**

<https://multiplemyelomahub.com/>

- Which actionable mutations in MM are the MMRF testing in their MyDrug initiative?
- Why should we perform PET-CT in a patient with SMM?
- Efficacy and feasibility of dose/schedule-adjusted Rd-R in elderly, intermediate-fit patients
- Mass-Fix for M-protein measurement in multiple myeloma

## **Cancer.com**

<https://www.cancer.com/>

## **Patient Power**

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

- Patients and Doctors Manage Multiple Myeloma Side Effects Together
- The Use of Selinexor (Xpovio) in Multiple Myeloma Treatment
- What Have We Learned About Selinexor (Xpovio)?
- Tips for Selinexor (Xpovio) Side Effect Management
- STOMP Clinical Trial Tests Selinexor Combination Therapies
- Venetoclax Effectively Targets B-Cell Multiple Myeloma

### **American Society of Hematology (ASH)**

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

- Idecabtagene Ciloleucel Induces Deep Responses in Relapsed/Refractory Multiple Myeloma
- Lenalidomide and Dexamethasone for Older Patients With Multiple Myeloma: Less Is More
- How Can the Myeloma Community Reduce Disparities in Care?

### **Blood Journal**

<https://ashpublications.org/blood>

### **The Lancet**

<https://www.thelancet.com/>

### **Healio**

<https://www.healio.com/>

## **Leukemia/Lymphoma Society (LLS)**

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

- May 25, 2021 6:00 pm - 7:30 pm (Via Zoom)
- Treatment to Transplant:

### **Making Informed Choices About Stem Cell Transplantation**

- <https://na.eventscloud.com/ehome/index.php?eventid=618637&>
- Speakers: Michelle Donato, MD – John Theurer Cancer Center, Hackensack...Dennis Cooper, MD – Rutgers Cancer Institute of NJ...Anita Kumar, MD – Memorial Sloan Kettering Cancer Center

## **MYeloma Channel**

<https://myelomachannel.com/>

## **Jama Oncology**

<https://jamanetwork.com/journals/jamaoncology>

## **Patient Empowerment Network**

<https://powerfulpatients.org/help-by-cancer-diagnosis/multiple-myeloma/>

- Which Myeloma Patients Should Consider Stem Cell Transplant?
  - <https://powerfulpatients.org/2021/03/31/which-myeloma-patients-should-consider-stem-cell-transplant/>

## Managing Myeloma

<https://www.managingmyeloma.com/>

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### International Myeloma Foundation

- COVID-19 Vaccination and Myeloma Patients
  - <https://www.myeloma.org/covid-19-vaccination-myeloma-patients>
- What the New CDC Guidelines Mean for You
  - <https://www.myeloma.org/cdc-guidelines-covid-19-masks>

### Myeloma Crowd

- Multiple Myeloma Patient Responses to the COVID Vaccine From UK Experience
  - <https://www.myelomacrowd.org/multiple-myeloma-patient-responses-to-the-covid-vaccine-from-uk-experience/>
- COVID Vaccine Responses Limited in Blood Cancer Patients
  - <https://www.myelomacrowd.org/covid-vaccine-responses-in-blood-cancer-patients/>

### **The Lancet**

- Response to first vaccination against SARS-CoV-2 in patients with multiple myeloma
  - [https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026\(21\)00110-1/fulltext](https://www.thelancet.com/journals/lanhae/article/PIIS2352-3026(21)00110-1/fulltext)

### **Leukemia/Lymphoma Society**

- COVID-19 VACCINES FAQ FOR PATIENTS AND CAREGIVERS
  - <https://www.lls.org/covid-19-vaccines-faq>