

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP

The Central New Jersey Multiple Myeloma Support Group met virtually on September 7, 2022 and there were 37 members and guests in attendance. We also welcomed one new member.

GUEST SPEAKERS: Jenny Ahlstrom, founder and president of HealthTree Foundation for Multiple Myeloma (formerly Myeloma Crowd), and a multiple myeloma patient. Also joining us was Rozalynn Hite, Myeloma Coach Director. In addition, our own member, Nov Griffin, who is a Myeloma Coach for HealthTree, spoke about her experiences as a MM Coach.

TOPIC: HealthTree Foundation for Multiple Myeloma web site, and programs offered by HealthTree.

Webpage: <https://www.myelomacrowd.org/myeloma/community>

Also, this is a great article on Jenny...

“How a cancer survivor turned a bad diagnosis into life-changing work”

Desert News, 2021...

<https://www.deseret.com/2021/12/26/22846731/how-a-cancer-survivor-turned-a-bad-diagnosis-into-life-changing-work-multiple-myeloma-healthtree>

If you haven't explored the HealthTree Foundation for Multiple Myeloma website, we would like to recommend that you do so. This is a great resource for MM patients and caregivers.

ANNOUNCEMENTS:

- Miracles for Myeloma 5k Run/Walk Virtual Edition
 - October 15, 2022
 - In person at Oak Ridge Park, in Clark NJ
 - If interested, you can donate, register as a runner/walker, join the Central New Jersey Support Group team, or create your own team. Visit <https://fundraising.myeloma.org/miraclesformyeloma>
 - If you cannot attend in person, you can sign up as a virtual participant, and run/walk where you live or on a treadmill, etc
- Jim Bond, 30 year MM survivor and our guest speaker from April 6, has sent the group additional information if you are interested...

“Some of your support group may be interested in 4 minute YouTube videos of what we've learned in 30 years. Below links to latest episodes; click videos at top to see all episodes”

https://youtube.com/channel/UCqLcRQUKliWxNh_4avhBysg

“Patient Empowerment Network posted a 1 hour myeloma patient video. 2 other patients and I shared our experiences.”

<https://powerfulpatients.org/2022/08/31/path-to-empowerment-multiple-myeloma-treatment/>

UPCOMING EVENTS:

- **Do You Know Myeloma?** A Two-Part Series on Facebook LIVE
 - Part 1: Do You Know Myeloma? Basics, Stats, & Facts About the Disease
 - September 21 at 4:00 p.m. PT/ 7:00 p.m. ET.
- **Part 2: Do You Know Myeloma Research?** Major research breakthroughs in myeloma, newly anticipated immune therapies, and IMF research under the Black Swan Research Initiative.
 - September 28th at 4:00 p.m. PT / 7:00 p.m. ET.
- **The LWM (Living Well with Myeloma) Webinar: Psychosocial Care/Common Support Needs and Coping Skills**
 - September 22, at 4 p.m. PST, 7:00 ET

Both available at <https://www.myeloma.org/>

AS ALWAYS, PLEASE CONSULT WITH YOUR HEALTHCARE TEAM...INFORMATION PRESENTED AT OUR MEETINGS AND ON THESE RECAPS IS FOR DISCUSSION PURPOSES WITH YOUR TEAM.

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SEPTEMBER 7 2022 VIRTUAL MEETING RECAP

INFORMATIONAL MYELOMA LINKS

International Myeloma Foundation

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

- Dr. Durie's Blogs
 - Will Amazon Deliver Your Healthcare Needs?
 - The limitations of artificial intelligence
 - The FDA EUA for new COVID-19 boosters
 - The science behind longevity and the "immortal jellyfish."
- September is Blood Cancer Awareness Month
- **Do You Know Myeloma? A Two-Part Series on Facebook LIVE**
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 - **September 21 at 4:00 p.m. PT/ 7:00 p.m. ET.**
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- **The LWM (Living Well with Myeloma) Webinar: Psychosocial Care/Common Support Needs and Coping Skills**
 - **September 22, at 4 p.m. PST, 7:00 ET**
- COVID-19 and Myeloma: What You Need to Know
- What is Multiple Myeloma
 - Newly Diagnosed
 - Testing/Staging

- Treatment
- Videos and Publications
 - IMF Publications
- Videos
 - Ask Dr. Durie
 - Are myeloma patients being cured when treated early and aggressively?
 - Should myeloma patients continue to follow COVID-19 prevention measures?
 - Patient/Family Webinars
 - Back to Basics: From Testing to Tailored Therapy
- Resources and Support
 - IMF Support Network
 - Diversity
 - External Resources
- Research
 - IMF Medical Research
 - Nurse Leadership Board
 - IMF Research Awards
- InfoLine
 - 800-452 CURE (2873)
 - info@myeloma.org
- M-Power

- <https://mpower.myeloma.org/>
- Veterans Against Myeloma (VAM)
 - <https://www.myeloma.org/veterans-against-myeloma>

The Multiple Myeloma Research Foundation

<https://themmrf.org/>

- Day 1 Highlights from the 19th International Myeloma Society Annual Meeting
 - <https://themmrf.org/2022/08/26/day-1-highlights-from-the-19th-international-myeloma-society-annual-meeting/>
- Day 2 Highlights from the 19th International Myeloma Society Annual Meeting
 - <https://themmrf.org/2022/08/27/day-2-highlights-from-the-19th-international-myeloma-society-annual-meeting/>
- Day 3 Highlights from the 19th International Myeloma Society Annual Meeting
 - <https://themmrf.org/2022/08/28/day-3-highlights-from-the-19th-international-myeloma-society-annual-meeting/>
- Resources
 - Education Programs
 - Financial Assistance
 - Myeloma Mentors

HealthTree Foundation for Multiple Myeloma (Formerly Myeloma Crowd)

<https://healthtree.org/myeloma>

- News
 - IMS 2022 In Review with Saad Usmani, MD, Memorial Sloan Kettering
 - An Off-the-Shelf CAR T Clinical Trial for Relapsed or Refractory Myeloma Patients (ALLO-715)
 - Clinical Trial: An Allogeneic CAR-T for Myeloma
 - IMS 2022: Moving Towards A Cure for Multiple Myeloma
 - Ide-cel (Abecma) Shows Better Results Compared to Standard Myeloma Treatment in Relapsed Patients
- Myeloma Basics
 - All About XGEVA (Denosumab) - video
 - How Are Myeloma Patients Treated Based On Frailty? – video
 - How is Frailty Defined in Multiple Myeloma?
 - Understanding the Difference Between Chemo and Immunotherapies in Myeloma with Dr. Scott Goldsmith
- Research
 - Nutrition Perceptions and Practices
- HealthTree Press
 - Multiple Myeloma Patients

- Myeloma Crowd Changes Its Name to HealthTree Foundation for Multiple Myeloma
- Cure Hub
- HealthTree University
- HealthTree Myeloma Coach
- My Journal
- Myeloma Chapters
- Events
- Podcasts
- Past Round Tables

HealthTree University Myeloma – YouTube

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

Myeloma Central

<https://myelomacentral.com/>

Cure

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

- Addition of Empliciti to Combination Regimen Continues to Show Benefit in Previously Treated Multiple Myeloma
- ‘Mounting Evidence’ Suggests Exposure to Environmental Toxins Plays a Role in Onset of Myeloma, Says Expert

- Sarclisa Delivered Through Under-the-Skin Injection Shows Promise in Patients With Pretreated Myeloma

Cure Talks

<https://www.curetalks.com/category/cancer/multiple-myeloma/>

OncLive/OncLive Videos

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

- CANDOR Trial of Daratumumab Plus Carfilzomib and Dexamethasone in R/R MM
- Real-World Data Highlight Efficacy of Ide-cel in Patients With Relapsed/Refractory Multiple Myeloma
- Treatment of Patients With MM and High-Risk Cytogenetics
- Selecting the Appropriate Patients With MM for Treatment With Isa-Kd
- Single-Agent Belantamab Mafodotin Elicits Activity in Heavily Pretreated Patients With R/R Myeloma
- Cilta-cel Induces Favorable MRD Negativity Rates in Heavily Pretreated Myeloma After Prior BCMA-Directed Therapy
 - <https://www.onclive.com/view/cilta-cel-induces-favorable-mrd-negativity-rates-in-heavily-pretreated-myeloma-after-prior-bcma-directed-therapy>

Myeloma Research News

<https://myelomaresearchnews.com/>

- Abecma May Be Effective Early Therapy for Hard-to-treat Myeloma
- Telo, Mayo Clinic Working on Tests to ID Patients at Risk of Relapse

Multiple Myeloma Hub

<https://multiplemyelomahub.com/>

- Current perspectives on circulating tumor cells in newly diagnosed MM eligible for transplant
- Teclistamab receives EMA conditional marketing authorization

Cancer.com

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

Patient Power

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

American Society of Hematologists (ASH)

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

Blood (ASH Journal)

<https://ashpublications.org/blood>

- How I approach smoldering multiple myeloma

- <https://ashpublications.org/blood/article/140/8/828/485274/How-I-approach-smoldering-multiple-myeloma>

Leukemia/Lymphoma Society (LLS)

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

- Study from The Leukemia & Lymphoma Society Provides New Information on How Blood Cancer Patients Respond to COVID-19 Vaccines
- Community Support
- Speak to an Information Specialist
- Financial Support

The Patient Story

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

Cancer Network

<https://www.cancernetwork.com/search?searchTerm=multiple%20myeloma>

- Is There a Role for MRD-Response Adapted Therapy in Transplant-Eligible NDMM?
- Comparing Combination Treatment Regimens in Transplant-Eligible NDMM
- Racial Disparities in the Treatment of Multiple Myeloma Patients

- Unmet Needs of Transplant-Ineligible Multiple Myeloma
- Elotuzumab Combo Significantly Improves Survival Vs Pomalidomide/Dexamethasone in Relapsed/Refractory Multiple Myeloma
- Determining Treatment Duration for Transplant-Ineligible Multiple Myeloma
- Maintenance Therapy in Transplant-Ineligible Multiple Myeloma
- Phase 3 KarMMa-3 Trial Meets Primary End Point of PFS With Ide-Cel in R/R Multiple Myeloma
- Rafael Fonseca, MD, Talks Future of Multiple Myeloma With Off-the-Shelf Cellular Therapies
- Plus, more!

Patient Empowerment Network

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

Managing Myeloma

<https://managingmyeloma.com/>

The ASCO Post

<https://ascopost.com/search-results/?q=multiple+myeloma>

- Bispecific Antibodies and the Dawn of a New Era in Treatment of Multiple Myeloma

- Study Examines Efficacy of T-Cell Redirection Therapies for Patients With Relapsed Multiple Myeloma
- BCMA x CD3 Bispecific T-Cell Redirecting Antibody ABBV-383 in Relapsed or Refractory Multiple Myeloma
- Final Analysis of GRIFFIN Study Presented for Daratumumab-Based Investigational Quadruplet Regimen in Newly Diagnosed, Transplant-Eligible Patients With Multiple Myeloma
- Durability of Responses to BCMA CAR T-Cell Therapy in Patients With Multiple Myeloma May Depend on Specific Components of the Tumor Microenvironment
- Prevalence of MGUS Among Rescue and Recovery Workers Exposed to the World Trade Center Disaster
- Racial/Ethnic Representation in Pivotal Clinical Trials for Drugs Approved for Leukemias and Multiple Myeloma

Smart Patients

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