

**CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP  
FOR FEBRUARY 5, 2020 WITH INFORMATIONAL LINKS**

This was an open meeting...

We welcomed 2 new members

Thank you to Adrienne and Roger for picking up our refreshments for this meeting

**Support Group Annual Survey**

One of the main focuses of this meeting was the discussion of the results of the support group Annual Survey.

**Somerset Patriots Baseball Game**

As in the past, our group's name has been entered in the Somerset Patriots Baseball Team Lottery for free tickets. This will be a group of tickets to an upcoming Patriots game. We will not know the date of the game until we know if we are awarded the tickets or not. Fingers crossed!

**Miracles for Myeloma 5K Run/Walk Grant Award Presentation at ASH 2019 Update**

Ron and Sheree Pask spoke to the group about the Miracles for Myeloma Grant presentation at ASH 2019.

Mark your calendars!!!

Miracles for Myeloma 5K Run/Walk 2020 will be held on Saturday, September 26, 2020. Hope to see you there, and plan on being inspired!!

**More walking...**

April 19, 2020

"Stroll the Shore for a Cure" in Pt. Pleasant, NJ

<https://independent.themmr.org/stroll-for-a-cure-2020>

April 25, 2020

Miles for Myeloma 5k Run/Walk in Philadelphia, PA

[http://give.myeloma.org/site/TR?fr\\_id=2021&pg=entry](http://give.myeloma.org/site/TR?fr_id=2021&pg=entry)

We have begun to rekindle the relationship with the Philadelphia Multiple Myeloma Networking Group, that was started many years ago by our group's founder, Paula Van Riper. Some members of their support group walked in the Miracles for Myeloma 5K 2019 here in NJ, and we are hopeful that our group can support their 5K in Philadelphia as well.

### Refreshment Update

I spoke to the group about last month's refreshment discussion and the budget we have for refreshments. The idea was presented last month, that a member would sign up for a meeting, and pick up and be reimbursed for refreshments for that meeting. I have been able to work out a contract with a local catering company who will provide and deliver refreshments within our monthly budget amount (If you attended our October meeting, the refreshments were provided by them as well). We took a vote and a majority of the members were in favor of having this catering company provide our refreshments for the future. If you signed up for an upcoming month, you will no longer be responsible for refreshments.

### March is Myeloma Action Month (MAM)

The International Myeloma Foundation has declared March to be Myeloma Action Month! (visit the Myeloma Action Month website for information,

<https://mam.myeloma.org/>). The MAM theme this year is "RESILIENCE".

In keeping with this "Resilience Theme", for our March meeting, our theme will be

**"OUR SKILLS AND TALENTS ARE WHAT DEFINE US, NOT MYELOMA"**

**We are asking all of you who will be in attendance to share “your talents”. This is important for caregivers as well as patients, because you are not just a “caregiver”. Many of you have talents...artists who paint, who create with woodworking, who quilt with love, who create beautiful articles of clothing, who write impressive books. And there are others who may have beautiful gardens or houseplants, who cook gourmet meals or bake beautiful and delicious cakes and cookies, who can run a 5K with an impressive time, who can ski or maybe sail. I think you get the idea. This meeting is for all to share, whether or not you will be sharing a specific talent, and to be inspired. You may bring to the meeting the actual objects of your talent or photos of them.**

**Please respond to this email if you will be participating and if you will be needing a full or half table, so that we can plan on the room setup. Also, if you can arrive a little before 6:30 pm to set up, that would be great.**

**We will take time during the meeting to discuss how other activities in our lives help to keep us all resilient on our myeloma journey. We will be making a video, so try to think of a statement for the video of why your talent helps to keep you resilient, but your participation in the video is voluntary. We are hopeful that this will be a very inspirational meeting, whether or not you have a talent to share.**

**Also, you will find on the MAM website, action you can take to make others aware of multiple myeloma and its symptoms...you can make a difference in whether the next MM patient is misdiagnosed or not. Download the “Patient Action Letter”, and send it to internists, orthopedics, emergency medical centers, etc. in your town. <https://mam.myeloma.org/patient-action-letter/>**

**Another way to take action, is to put a press release in your local paper or “Patch” regarding myeloma facts and symptoms, the efforts of the International Myeloma Foundation, and our support group. (for those who are unfamiliar with the “Patch”, most towns have a “Patch” that posts local town information. For example, our support group meetings are listed in the Bridgewater Patch. The article you post is free of charge. Search the “Patch” for your town to see if you have town Patch, or if your area is included with other towns.) You can download the “Press Release” from the MAM website, <https://mam.myeloma.org/mam-press-release/>**

## **Upcoming Meetings**

**April – Celgene Clinical Nurse Educator – A presentation on “Understanding Lab Values”**

**May – Spring Celebration of Life Event – This is a catered dinner event, free of charge for all members, their families and/or close friends. An invitation will be sent out late March or early April. This will be another special evening, as we will be having a theme for this year’s event.**

### **RESILIENCE**

**In keeping with this year’s MAM theme, we will be sharing our resilience in an emotional and inspirational “Wall of Resilience”. We will be asking our members to bring in a photo of something/someone/somewhere, etc., that gives them resilience or is a picture of resilience. You will also be asked to bring a written/typed short paragraph or statement of why you chose this photo. We will be hanging these photos and statements, and create a “Wall of Resilience”. More to follow!**

**June - MMRF, Multiple Myeloma Research Foundation – We will have a speaker speak to the group about the many research programs the MMRF is involved in.**

**July - No meeting**

**August – TBD**

**September – TBD**

**October – Dr. Toomey, Hematologic Oncologist from Steeplechase Cancer Center and possibly a Social Worker from Steeplechase as well.**

**November – Kelley Sidorowicz, Regional Director, Support Groups for the IMF**

**December – TBD**

## INFORMATIONAL LINKS

**International Myeloma Foundation**

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

**Catch Up with ASH 2019**

<https://www.myeloma.org/imf-ash-2019>

**WHAT IS MULTIPLE MYELOMA?**

<https://www.myeloma.org/what-is-multiple-myeloma>

- **Are You Newly Diagnosed?**
- **Do You Have Myeloma?**
- **What Are MGUS, Smoldering Myeloma, and MM?**
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- **Treatment**
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- **Clinical Trials**
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- **FAQ**
- **What Is Multiple Myeloma?**

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- Contact the InfoLine - 800-452 CURE (2873)
- Publications and Videos
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- Additional Resources
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- **Can infections, such as Helicobacter pylori, trigger multiple myeloma?**
- **What is Isatuximab? And how does it compare with daratumumab?**
- **Should FiSH testing be done at relapse?**

#### **Dr. Durie's Week in Review**

<https://www.myeloma.org/week-review-dr-brian-gm-durie>

- **Black Swan Research Projects Forge Ahead in 2020**
- **Don't freak out: start the new year healthy and positive**

#### **Co-pay Assistance Programs Update (1/17/2020)**

<https://www.myeloma.org/copay-assistance-update>

#### **Amazon Smile**

<https://www.myeloma.org/donation/amazon-smile>

**“Shop and Give at the Same Time”**

**“When you select the International Myeloma Foundation as your preferred charity from AmazonSmile, Amazon gives to the IMF—at no added cost to you!”**

## **Myeloma Action Month**

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**“The IMF is gearing up for March — Myeloma Action Month (MAM)! This year, the IMF is focusing on resilience. Exclusive “I AM RESILIENT” merch is available for a limited time only. Explore the site to learn how you can make a difference this MAM.”**

## **Veterans Against Myeloma**

<https://www.myeloma.org/veterans-against-myeloma>

## **Multiple Myeloma Research Foundation**

<https://themmrf.org/>

## **Supportive Care Webinar**

[https://event.webcasts.com/starthere.jsp?ei=1282070&tp\\_key=c10847c563](https://event.webcasts.com/starthere.jsp?ei=1282070&tp_key=c10847c563)

**March 4, 2020**

**1:00 PM–2:00 PM (EST)**

**“...webinar was developed to help patients with multiple myeloma manage fatigue, risks for bone fractures, infections and other complications that can result from myeloma or from anti-myeloma therapies.”**

## **MMRF Patient Navigator Team**

<https://themmrf.org/multiple-myeloma/resources/talk-to-a-nurse/>

**Speak to an MMRF Nurse Patient Navigator**



An MMRF Nurse Patient Navigator can guide you through your multiple myeloma journey every step of the way. Call Monday – Friday, 9 AM -7 PM ET [1-888-841-MMRF\(6673\)](tel:1-888-841-MMRF(6673)) or [email patientnavigator@themmrf.org](mailto:patientnavigator@themmrf.org)

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- What is Multiple Myeloma?
- Symptoms, Side effects and Complications
- Prognosis
- Diagnosis
- Treatment Options
- Resources

## **Immune Networks of Excellence Meeting – January 2020**

<https://themmrf.org/2020/01/immune-networks-of-excellence-meeting-january-2020/>

## **How We're Curing Multiple Myeloma**

<https://themmrf.org/we-are-curing-multiple-myeloma/>

- Our Model
- Strategic Plan 2019
- Results
- MMRF CoMMpass Study
- MyDRUG
- MMRF CureCloud

- MMRC
- Research Grants

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- Good News for Myeloma Patients: Steadily Improving Outcomes With "Total Therapy"
- Clinical Trial: Smoldering Myeloma Personalized Vaccine at MD Anderson
- Myeloma Coach – Find a Myeloma Coach or Find Out How to Become a Myeloma Coach
- New Myeloma Combo (carfilzomib/Dara/dex) Submitted for FDA Approval
- Reducing CAR T Side Effects in Multiple Myeloma
- And More

### HealthTree

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

“HealthTree is a free, new tool created by myeloma patients for myeloma patients. HealthTree is an online tool myeloma patients can use to navigate their care while also helping advance a cure”

### Healthtree University (on line videos)

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

### Myeloma Crowd Radio

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

- **Full Show: Multiple Myeloma Progress for 2020 with Robert Orlowski, MD, PhD, MD Anderson Cancer Center**
- **Full Show: Myeloma Care in Patients Over 65 with Tanya Wildes, MD, Siteman Cancer Center**

## **Myeloma Beacon**

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- **Janssen Announces Submission To U.S. FDA For New Darzalex (Daratumumab)-Based Combination Regimen For Patients With Relapsed / Refractory Multiple Myeloma**
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- **US Food And Drug Administration (FDA) Grants Priority Review Of Belantamab Mafodotin For Patients With Relapsed Or Refractory Multiple Myeloma**

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- **Patients with Multiple Myeloma Give Themselves Hope Through Treatment**
- **Three-Drug Combination Improves Progression-Free Survival in Patients with Multiple Myeloma**

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- **Understanding the Role of Immunoglobulins in MultipleCure Connections – Myeloma**
- **And More**

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- **Multiple Myeloma in African Americans**

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**American Society of Hematology**

<https://hematology.org/>

**Myeloma Hub**

<https://multiplemyelomahub.com/>

**Cancer.com**

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## ASH Clinical News

<https://www.ashclinicalnews.org/?s=multiple+myeloma>

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<https://multiplemyelomahub.com/>

### **Cancer.com**

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

### **ASH Clinical News**

<https://www.ashclinicalnews.org/?s=multiple+myeloma>