

## Central New Jersey Multiple Myeloma Support Group Meeting Recap for Wednesday, February, 1, 2017

This was an open meeting. The following topics were discussed...

We welcomed 2 new members Debbie and Toby, and heard about their myeloma journey.

Announcements:

- The MMRF is offering a 2-part caregiver webinar
  - Part 1 –Thursday, February 23, 2017 from 1-2 pm EST. “The New Normal for Caregivers of Patients with Multiple Myeloma”
  - Part 2 –Thursday, March 16, 2017 from 1-2 pm EST. “Managing the Ups and Downs of Caring for a Multiple Myeloma Patient”Go to “TheMMRF.org” website, scroll down to “Patient and Professional Education Programs”, and click on Feb 1, 2017.
- The IMF is offering a “Patient/Family Seminar” on April 7<sup>th</sup> and April 8<sup>th</sup> 2017 at the Short Hills Hilton, in Short Hills NJ. You can call to register to attend at 800-452-2873, or visit [Shorthills2017.myeloma.org](http://Shorthills2017.myeloma.org).
- There is now a Facebook page for our support group. You can visit without joining Facebook.
- ASH Summary (from the MMRF)  
CoMMpass Study results
  - It was reported that all drugs work better in combination, and that studies showed that patients didn’t see the benefit of a second transplant, back-to-back after the first. Also, the newer therapy drugs were discussed.

## Celebration of Life Event 2017 Feedback Discussion:

I led the discussion starting with feedback on the food for the Celebration. This year the food was not served hot (action to be taken with caterer next time). We will try to have the food selections labeled, and a list of ingredients for those items stuffed, etc. This will help those with diet restrictions. The 50/50 was a success. The amount sent to the IMF was \$453.00, and I have requested that these monies be applied to the "Central Jersey Memorial Team" for the Miracles for Myeloma 5K 2017. Attendance this year was down from previous years, but there were members with other plans, less family members invited, less members of the band Waterstreet invited (because of room size), and some last minute cancellations. All in all the evening was a success in my opinion. We then had an open discussion on this matter, and the following suggestions were made...

Due to the time of year for the Celebration, it may be difficult for people to attend. This year's event was held too close to the New Year's Eve holiday. The winter weather may also discourage many from attending. Springtime may be a better time of year.

The 50/50 made for a more relaxed atmosphere than previous years with the raffle donations. It was also suggested to be sure that those not able to attend the Celebration were made aware that they were welcome to be a part of this activity, and that members may offer to sell the 50/50 tickets to others not in our support group.

It was suggested that we try to have the Celebration at a restaurant or hall next year. This would allow for a festive time with friends and family out of a medical facility. This would have to fit in with our budget as well. I will check with my contact at

Takeda to see if they have any suggestions. If anyone is interested in working with me on this task, please respond to this email.

MAM (March is “Myeloma Action Month):

[www.MAM.myeloma.org](http://www.MAM.myeloma.org)

Here are the activities we are doing as a support group this year.

1) News Release: I will be sending a news release regarding myeloma awareness (this section provided by the IMF) and our support group to 3 newspapers...The Star Ledger, Courier News, and Daily Record. After these articles are in print, a link to them will be sent to the IMF and they will be posted on the MAM website under the section “News Article”. Attached is a copy of this news release. If you would like to contact a newspaper in your area, go to their “contact us” section to see where you will need to email this news release. Please let me know which paper you have contacted.

2) Mannequin Challenge: This is a new, upbeat, and enjoyable way to share a video. At the meeting, we made our own “Mannequin Challenge” video (for those of you who do not know what this is, a video is taken as those being videoed freeze!). The inspirational quote (thank you Ron) for our video is...”Though we are standing still, we are moving to find a cure”. The video should be available for you all to view shortly.

Here are the ways you can support Myeloma Awareness Month...

1) “Music 2 Fight Myeloma” on the app “Spotify”. Spotify is a free app for listening to music. Download the app, search for “Music2fightMyeloma”. Click “follow” (you can save the song set too!) and for each “follow”, Takeda will donate money to the IMF. You may need to Google search “Music 2 Fight Myeloma Spotify” if you have a problem.

- 2) “Donate a Photo” – This is another app. Choose “global disease challenges”. You may “donate” 1 photo per day...your dog, your garden, yourself, your beautiful dinner menu! For every photo donated, J & J will donate \$1 to fund myeloma research. The MMRF has just completed their campaign, and funded 71 hours of research. The IMF campaign has not started yet, so please check the “Donate a Photo” website.
- 3) “Shop for the IMF” on Amazon – By using <http://amazon.myeloma.org> as your way to shop on Amazon, Amazon will donate up to 6% of your purchase to the IMF. Last year, almost \$5,000 was donated to the IMF.
- 4) “Charity Miles” app – Download this free app and your exercise will matter to others! You can choose to walk or bike outside using GPS, or walk inside. Choose LLS (Leukemia/Lymphoma Society) as your cause (this will also support multiple myeloma). J & J will donate to LLS, with the total earned so far \$114,226. You will notice, “Donate a Photo” comes up here as well.
- 5) “Share your Story” – This is found on MAM.myeloma.org. You can share your myeloma journey and it will be posted on the MAM website.
- 6) “Patient Action Letter” – Attached you also will find a general “Patient Action Letter” if you are interested in mailing it to physicians, etc. in your area, so they are aware of the symptoms of myeloma. Many times chiropractors, orthopedists, and Emergency Centers are the first places patients may visit before a diagnosis is made, and doctors in these offices may be unaware of myeloma symptoms.
- 7) “MAM Flyer” – This is also attached. If you are interested, make copies and post them around your area. It was suggested “Over 50 Communities” may be a good place to post a flyer, as well as libraries, grocery stores, etc.

- 8) “Proclamation” – H. Resolution 174 “Designating March as National Multiple Myeloma Awareness Month” is still in the House of Representatives. A quick way for you to support this resolution is to go to the IMF website, [www.myeloma.org](http://www.myeloma.org), then choose “get involved”, then “be an advocate”, then “myeloma action center”, then “click here to learn more...”, finally “take action”. There you can follow the directions to support this resolution on line.
- 9) “Share Your Action” – back to MAM.myeloma.org to the “Share Your Action” choice. After you have completed any of the ideas above, share what you have done to inspire others.
- 10) “3 Points for Patients” – This is just a fun event to follow, especially if you are a basketball fan. This is between the Boston Celtics and Takeda. For each 3 pointer made by the Boston Celtics, Takeda will make a donation to the IMF.

#### First Quarter Support Group Leaders Call on 1/31/17 Recap:

I represented the support group on this call and there were a few helpful items I shared at the meeting.

- IMF Infoline and Myeloma Matrix 2.0 – ([www.myeloma.org](http://www.myeloma.org), then “advancing treatment”, then “clinical trials”). In 2015, the IMF received a grant from Celgene in remembrance of Michael Katz, patient and board member, and partnering with The Smart Patients, Myeloma Matrix 2.0 was created. Myeloma Matrix 2.0 shows all new and existing myeloma trials, shown in real time...updating immediately and continuously. You can search for a drug trial by drug class type, drug name, trial phase, location of a trial near you, or where you are in your disease process. By clicking on a drug trial box, details about that trial will be shown.
- Resources – the following are resources for help with drug costs
  - Go to [www.myeloma.org](http://www.myeloma.org), then “providing help”, then “other online resources”, then “drug reimbursement & assistance”.

This will show you a list of resources for reimbursement of copays, etc. for patients.

- For each drug company (ex: Celgene, Takeda), go to the “Patient Support or Assistance” option, and they will evaluate your benefits for helping with payment options.
- SHIP – State Health Insurance Program  
[www.nj.gov/humanservices/doas/services/ship](http://www.nj.gov/humanservices/doas/services/ship) – This is for Medicare and Medicaid patients. This is a New Jersey, non-biased insurance program.
- [www.Q1Medicare.com](http://www.Q1Medicare.com)  
This resource is helpful if your medication is not covered by Medicare Part D, and has other informative Medicare Part D information.

#### Speakers:

- The topic of speakers for the support group was discussed. Most of the attendees were in favor of more speakers throughout the year. Also a support group survey was distributed regarding speaker topics and general support group format. The scheduled speakers to date are  
Holly Wall – Ninlaro Presentation – March  
Robin Tuohy – May

Other possible speakers without a set date...

Bristol Myers/Squibb – Empliciti,  
Caregiver Presentation by Takeda,  
Dr. Gharibo.

Your speaker suggestions are always welcome.

Ash 2016:

Sheree and Ron Pask discussed their attendance at ASH 2016 and the presentation of a Senior Grant in the amount of \$78,000 that the Miracles for Myeloma 5K 2016 funded. The grant was presented to Dr. Karin Vanderkerken. Her topic of study is "Targeting Residual, Dormant Cancer Cells in Myeloma: A New Approach".

Recaps are now available for you to view on our group's web site ([centralnj.support.myeloma.org](http://centralnj.support.myeloma.org)). The current recap will be there, as well as past recaps.

Fun and Final Note: The Empire State Building will be lit in burgundy in March for Myeloma Awareness. Check on line for an update on the date of the lighting.

This was a lengthy recap but there was so much valuable information discussed. Stay well.

Debbie Morelli