

**CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP
RECAP FOR WEDNESDAY, FEBRUARY 6, 2019**

This was an open meeting...

In an effort to reduce the chance of future problems with the email failure we have experienced, this recap and all future recaps will only include information discussed at our meeting. A separate attachment will be added to include the additional important information and links. The monthly recaps that are posted on our web page, however, will include all the links as one recap.

IN CASE OF INCLEMENT WEATHER, OUR WEB PAGE

centralnj.support.myeloma.org

**WILL HAVE A MEETING CANCELLATION NOTICE POSTED BY 3:00 PM
THE DAY OF THE MEETING. WE WILL ALSO SEND OUT A MEETING
CANCELLATION EMAIL BY 3:00 PM AS WELL**

A summary of our Support Group Survey was the main focus of our meeting. Below is an overview of the Survey results...

SURVEY RESULTS SUMMARY (23 Responded)

**(The numbers after the following answers represent the number of
members with the same answer)**

1) What speaker / topic did you find most helpful over the past year (20 responses)

**Dr Biran – 6 New Therapies - 6 Health Insurance – 1
Dietician – 1 Nurse Educators – 4 Transplants – 1
IMF Speakers – 1 Cancer Survivorship – 1 CAR T-cell – 2
Dr. Hinic, oral surgeon – 1 Linda Schmidt, nurse – 3**

2) Do we want to invite any of the past speakers back for additional information? If so, whom? (20 responses)

**Dr Biran – 5 Linda Schmidt, Nurse – 3
Dr Hinic, oral surgeon – 2 Drug Therapies – 2
New therapies – 2 Nurse Educators – 1
A few “don’t know” and “no one” responses**

3) What speaker/topics are of the most interest to you in the upcoming year? (23 responses) – multiple choice, a “choose all of interest” question

**Understanding Lab Values – 70%
New Drug Therapies/Clinical Trials – 65%
Nutrition for Cancer Patients– 48%
Exercise/Physical Activities for MM Patients – 48%
CAR T-Cells – 48%
Side Effects/Pain Management – 39%
Round Table Discussion on How to Effectively Talk to Your
Doctor – Led by Support Group Members – 39%**

Myeloma 101 – 35%
**Social Worker to Discuss Stress Management and
Psychological Effects of Living with Cancer – 30%**
Medicare – 26%
Health Insurance Open Enrollment Options – 17%
Stem Cell Transplant – 17%
Resources for Caregivers – 13%
Legal Issues – 13%

4) Additional Speaker Suggestions? (15 responses)

**Other MM specialists (Memorial Sloan Kettering Cancer
Center, Dr. Siegel, Dr. Vesole, Rutgers
Cancer Institute of NJ)**
Stress and fatigue
Neuropathy
Motivational patient speakers
**When to get second opinions and travel out of state
also**
No drug specific speakers from pharma

**5) How Often Would You Like to Have a Speaker Come and Speak
to Our Group? (21 responses)**

86% every other month
9.5% once a quarter
5% other

**6) What Do You Find Beneficial About Our “Open Meetings”?
(21 responses)**

All positive comments about our open meetings

7) Any Recommendations to Improve our “Open Meetings”?

Limit the time each member speaks (this is a recurring recommendation)

Have a theme for our “Open Meetings”

Pre-Submit topics or questions for our “Open Meetings” (as a note, when our meeting announcement is sent out, it is always mentioned you are welcome to submit any questions for the upcoming meeting)

Chromosomal abnormalities

Successes, treatments, diets, exercises

There was also a lot of positive “Open Meeting” feedback

8) Why Do You Attend Our Support Group? (22 responses)

Dialogue with Others – 16 members

Speakers – 15 members

Information – 14 members

Support – 13 members

Fellowship – 11 members

9) Are There Any Other Recommendations for Our Group You Would Like to Share? (14 responses)

Speakers and MM specialists from other hospitals

The remainder of the responses consisted of positive feedback as to how our group is doing

After the Survey results were presented, a discussion was held. The following suggestions were also made ...

SPEAKERS AND SPEAKER TOPICS

- Neuropathy
- Social Worker speaking about “how to deal with this disease”
- Physical fitness and myeloma
- Physician to speak about the health side effects...diabetes, high blood pressure, cataracts, etc. a myeloma patient may be experiencing
- Physician to speak about specific drugs and how to cope with side effects
- Oncology Massage Therapist
- Call-in meeting or skype with a myeloma specialist who is not in our area

SUGGESTIONS

- Ask speakers to bring slide-deck printouts if using Power Point for their presentation and/or bring hand-out materials pertaining to their presentation (booklets, printouts, etc)

- Ask myeloma specialists who treat our members, but may not be in our support group area, to add a visit to speak at our group, when they are in this area for other business

IF YOU ARE INTERESTED, REACH OUT TO YOUR MYELOMA SPECIALIST AND SEE IF THEY WOULD BE INTERESTED IN SPEAKING TO OUR GROUP!

Other topics of interest

SPRING CELEBRATION OF LIFE EVENT - MAY 1, 2019

MARK YOUR CALENDARS!!! Our Spring Celebration of Life Event will be held on Wednesday, May1, 2019 in lieu of our regular support group meeting. We will meet in the 3rd Floor Conference Room of Steeplechase Cancer Center for an evening of catered hot/cold appetizers, dinner, and dessert. This event is provided to you at no charge, and your family and close friends are welcome to join you. In an effort to provide this event to you free of charge, grant applications have been submitted for monetary assistance, as well as donation requests from various food establishments. We are hopeful that our donations will again cover the cost of this event. If anyone has a personal contact, perhaps in the restaurant business for example, who would be willing to donate food for our event or a gift card for us to purchase food from their establishment, please feel free to contact them and let me know what they would be willing to donate. An invitation to the Event will be sent to you in April with complete Event details.

SOMERSET PATRIOTS BASEBALL GAME

As in the past, we have applied for complimentary tickets for a Somerset Patriots Baseball Game. These tickets are awarded through a lottery system, and if we are awarded the tickets, we will then know the date of the ballgame. We have been chosen in the past, so keep your fingers crossed it is our turn again this year! We will keep you all posted...

IMF PATIENT/FAMILY SEMINAR IN SHORT HILLS, NJ

On Friday April 5 and Saturday April 6, the IMF will be presenting another Patient/Family Seminar in Short Hills NJ. Friday's Seminar is from 1 pm – 5 pm and includes dinner. Saturday's Seminar is from 7 am- 4 pm and includes breakfast and lunch. If you have never been to a Patient/Family Seminar, we highly recommend it...and if you have been to one in the past, we highly recommend you attend again. The information presented and the Myeloma specialists invited to speak are amazing. Register online at shorthills2019.myeloma.org or call **800-452-2873** for more information.

“LIVING WITH MYELOMA” PROGRAM

On March 2, Takeda Oncology will present the program “Living with Myeloma” at the Teaneck Marriott. The guest speaker will be Dr. David Siegel, myeloma specialist from the John Theurer Cancer Center at HUMC. Dr. Siegel will speak about Ninlaro, and you will hear the story and treatment experience of a person living with multiple myeloma.

The event location is...

Teaneck Marriott at Glenpointe

100 Frank W. Burr Blvd

Teaneck, NJ 07666

The program begins at 10:00 am, with registration starting at 9:30 am. Please visit myelomaevent.com or call **1-844-247-1641** for more information.

MARCH IS MYELOMA ACTION MONTH! (or MAM)

March is Myeloma Action Month! It is time for all of us to take Action and to make others aware of this disease. Visit mam.myeloma.org and under **“TAKE ACTION”** you will see all the different ways that you can make a difference by “Taking Action”. You will find...

- A “Patient Action Letter” for you to download and use the fillable spaces to add information. Send this letter to General Practitioners in your area, Orthopedics, Emergency Medical Clinics, for example. There are still too many patients who are misdiagnosed with MM, because a doctor did not know the symptoms of MM or did not know the specific screening tests for this disease.
- Do you use Facebook? Directions can be found on how to “Donate Your Birthday”, a way for you to raise money for the IMF online in lieu of birthday gifts.
- Do you listen to music on the Spotify app? If not, Spotify is an app that allows you to listen to the music you like. (visit spotify.com for more information). During the month of March, follow Takeda

Oncology's "Music 2 Fight Myeloma" playlist, and Takeda will make a donation to the IMF.

Do you enjoy posting on Social Media? Under the tab **"GET SOCIAL"** you can find out how you can

- Post a Badge
- Add a Facebook Frame
- Compose a Tweet

What is a "Myeloma Warrior"? According to IMF Chairman of the Board Dr. Brian G.M. Durie, "Myeloma warriors are patients who seek out the best for themselves while also helping others." We all can become Myeloma Warriors!! Take a few minutes to visit mam.myeloma.org and see what you can do.

OR

Visit mam.myeloma.org and under the **"MERCHANDISE"** tab, view all the MYELOMA WARRIOR items for sale.

At our next meeting, we will be making a short video of our Myeloma Warriors, our patients fighting this disease and our caregivers. You will begin by stating... "I have been a Myeloma Warrior for ...(weeks/months/years)", if you are a patient, and then... "What does being a Myeloma Warrior mean to me?..." Or, What does being a Myeloma Warrior Caregiver mean to me...". We will be posting this video on our Facebook page and also on the IMF (mam.myeloma.org) page. Your statement should be one sentence long only.

Below is additional information and links that may be of interest to you...

The IMF is looking for positive stories for myeloma patients treating with Selinexor. If you have been on/are on Selinexor, and interested in sharing your story, please contact us at centralnj@imfsupport.org

“NYU Langone Health and its [Laura and Isaac Perlmutter Cancer Center](#) announced a transformational philanthropic gift to establish a Center for Blood Cancers that will house a new, world-class program for multiple myeloma care and research, along with its other blood cancer programs...”

www.myelomacrowd.org/anonymous-75-million-gift-funds-new-center-for-blood-cancers/

Information on Co-Pay Assistance from MM Facebook page...

As of February 11, 2019, the following Multiple Myeloma Patient Co-Pay Assistance Programs remain OPEN and have available funding.

HEALTHWELL FOUNDATION

- ~ Re-enrollment and New Patient enrollment.
- ~ MEDICARE Patients Only
- ~ Drug Co-Pay Assistance AND Insurance Premium Assistance
- ~ Call (800) 675-8416 OR
- ~ Enroll

electronically <https://www.healthwellfoundation.org/fund/multiple-myeloma-medicare-access/>

LEUKEMIA & LYMPHOMA SOCIETY (LLS)

- ~ Re-enrollment and New Patient enrollment.
- ~ Insured by Commercial Insurance or Medicare/Medicaid
- ~ Drug Co-Pay Assistance AND Insurance Premium Assistance
- ~ Call (877) 557-2672 OR
- ~ Enroll electronically <http://www.lls.org/support/financial-support/co-pay-assistance-program>

PATIENT ADVOCATE FOUNDATION (PAF)

- ~ Re-enrollment and New Patient enrollment.
- ~ Insured by Medicare/Medicaid or Military Benefits ONLY
- ~ Drug Co-Pay Assistance
- ~ Call (866) 512-3861 OR
- ~ Enroll electronically <https://www.copays.org/diseases/multiple-myeloma>

As of February 11, 2019, the following Multiple Myeloma Patient Co-Pay Assistance Programs remain CLOSED/FULLY ALLOCATED.

ASSISTANCE FUND

<https://tafcares.org/patients/covered-diseases/>

- ~ Insured by Commercial Insurance or Medicare/Medicaid
- ~ Drug Co-Pay Assistance
- ~ Call (855) 845-3663

CANCER CARE <http://portal.cancercarecopay.org/Funds-Available/Diagnoses>

GOOD DAYS <https://www.mygooddays.org/patients/diseases-covered/multiple-myeloma>

PATIENT ACCESS NETWORK FOUNDATION (PAN)

~ Re-enrollment and New Patient enrollment.

~ Insured by Commercial Insurance or Medicare/Medicaid

~ Drug Co-Pay Assistance AND Insurance Premium Assistance.

~ Call (866) 316-7263 OR

~ Enroll

electronically https://www.panfoundation.org/index.php/en/patients/assistance-programs/multiple-myeloma?fbclid=IwAR0biF4kLNAFzod7kLNI_w7RzArJhPmuca1CC2wFkKJBuwNH0FZbinkpX7g

The ASCO Post

<http://www.ascopost.com/topics/hematologic-malignancies/multiple-myeloma/>

IMF Website

www.myeloma.org

Co-Pay Assistance Update as of 2/12/19

www.myeloma.org/article/co-pay-assistance-programs-update

THE ISTOPMM PROJECT @ Year Two

www.myeloma.org/videos/istopmm-project-year-two

IMF Blogs

www.myeloma.org/blogs

Interesting blogs...

- *A MYELOMA WARRIOR WHO INSPIRED US ALL
- *OBESITY, MYELOMA, AND YOUNGER AGE OF ONSET
- *UNDERSTANDING IMMUNE MONITORING, AND WHY GLOBAL OBESITY IS ON THE RISE

IMF TV

www.myeloma.org/understanding/imf-tv

Interesting videos...

- *Is the combination of Velcade, Revlimid, and dexamethasone (VRD) helpful for myeloma patients over the age of 65?
- *What is a BiTE and how likely is it to help me to achieve a response and remission for my myeloma?
- *How do you tell if you're in remission?
- *Why do some doctors decide to add new treatment when myeloma protein levels increase, whereas other doctors decide to watch and wait?

Caregiver Resources

www.myeloma.org/caregiver-resources

Links to Caregiver Information and Organizations from the IMF...

[Atlas of Caregiving: Research, Data, and Solutions for Family Caregiving](#)

[Help for Cancer Caregivers](#)

Help for Cancer Caregivers is a unique collaboration of organizations with a shared goal of improving the health and well-being of the people who care for people with cancer. Please be sure to tell any caregivers you know about this site.

[American Cancer Society - Caregivers](#)

Learn about what to expect if you become a caregiver for a person with cancer, as well as find suggestions and tips for making sure that you take care of yourself as well.

[Cancer.net](#)

American Society of Clinical Oncology (ASCO) site defines the role of caregiver and the potential challenges caregivers face.

[Caregiver Action Network](#)

CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

[Caring Bridge](#)

A nonprofit providing free websites that connect family and friends—and ease the burden of keeping family and friends informed—during a serious health event, care and recovery. Authors add health updates

and photos to share their story while visitors leave messages of love and support in the guestbook.

[Coping with Cancer: For Caregivers, Family and Friends](#)

Information from the National Cancer Institute to help caregivers cope while caring for a loved one with cancer, as well as help someone with cancer talk about and cope with the illness.

[Family Caregiver Alliance](#)

Founded in 1977, FCA was the first community-based nonprofit organization to address the needs of families and friends providing long-term care at home. FCA now offers programs at national, state and local levels to support and sustain caregivers.

[Well Spouse Association](#)

The Well Spouse Association advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse/partner. They offer peer to peer support and educate health care professionals and the general public about the special challenges and unique issues "well" spouses face every day.

[BMT InfoNet](#)

Role of the Family Caregiver

Myeloma Research News

<https://myelomaresearchnews.com>

Interesting articles...

HOT OFF THE PRESS TODAY...Split Dosing of Darzalex Over Consecutive Days Approved by FDA for Multiple Myeloma Patients

*clonoSEQ Assay Now Covered by Medicare for Multiple Myeloma and Acute Lymphoblastic Leukemia

*Single-cell Profiling in Multiple Myeloma May Improve Diagnosis, Treatment, Study Suggests

*Measuring Blood Vessel Activity May Predict Multiple Myeloma Prognosis

*Donation Will Establish Center for Multiple Myeloma Research in UK

*Thalidomide at 100 mg Shows Benefits as Maintenance Therapy in Multiple Myeloma Patients in Trial

*Isatuximab Extends Time Without Cancer Progression in Phase 3 Trial of Multiple Myeloma

*Real-world Data Supports Use of Oral Triple Combination in Treating Advanced Multiple Myeloma, Study Finds

*\$75M Gift to Establish Center for Blood Cancers at NYU Langone Health Center

Other webpages....

myeloma central

www.myelomacentral.com

Myeloma Beacon

<https://myelomabeacon.org/>

Myeloma Crowd

www.myelomacrowd.org

Myeloma Crowd Radio

www.blogtalkradio.com/myelomacrowdradio

Multiple Myeloma Research Foundation

<https://themmrf.org>

In response to the number of members interested in hearing from a speaker regarding lab values, we are pleased to advise you all that Holly Wall, Clinical Nurse Educator from Takeda Oncology will be presenting a program called “Understanding Lab Values” at our March meeting.

AND FINALLY...

Please see the attached 3 documents, one with important myeloma information and links, a document from the IMF “Drugs in Current Use

for Multiple Myeloma as of November 2018”, and list of the MM drug classes as of June 2018. (In reviewing this list, you will see an initial in quotation marks under a drug. These are the initials that are used when referring to treatment combinations. For example, VRD is Velcade, Revlimid, Dex. I hope this list helps in this regard.)

We are looking forward to seeing you at our March 6 meeting. Wishful thinking that this will be our last meeting of the winter!! Spring is just around the corner. Stay well,

Debbie Morelli