

WEDNESDAY SEPTEMBER 6, 2017
CENTRAL NJ MM SUPPORT GROUP MEETING
RECAP

This was an open meeting...

Mike Caputo started the meeting by sharing the origin of our support group, and some background information on the group founder Paula Van Riper. The present Steering Committee members were introduced...

Mike Caputo

Sheri Goldberg

Diane Kranz

Wayne Kranz

Sheree Pask

Ron Pask

Mike then announced that Frank and I, have accepted the leadership role for our support group. We are honored to accept this opportunity and we look forward to supporting everyone and continuing to share our vision for the group.

The meeting continued by acknowledging Paula Van Riper's extremely personal contribution/connection to the group. Paula would reach out to prospective new members, and personally share her knowledge of the disease, her journey, and offer support and encouragement. When Paula passed away, the Steering Committee was reluctant to try to replace her personal connections with new patients, and instead directed new patients/members to the IMF (International Myeloma Foundation), as a place for them to speak to someone on their Hotline about this disease, gather information on treatments, and receive support.

Frank and I, and the Steering Committee feel we are now ready to continue Paula's personal connection to our members.

Our Vision

We are hoping our meetings and our support group, will have a more personal connection. From our members, we want to know

- What do you need from this group...what can the group do for you?
- What kind of meetings would you like to have?
- What speakers would you like to have come and address our group?
- Would you attend our meetings if you had transportation to and from the meeting?
- Would you attend our meetings if you had someone to attend the meetings with you?

Please contact Frank and I with your suggestions and concerns at the group email (centralnj@imfsupport.org).

We are going to make a greater effort to be sure you are doing well if we haven't seen you at meetings (and you regularly attend), haven't heard from you, or if we know you are having difficulty with your treatments or health. A new questionnaire was distributed and asked to be completed regarding emergency contact information, etc.

New Members

When a prospective new member reaches out to our group via the group's email, Frank and I will reach to them with a phone call or email conversation.

If a new member decides to attend one of our meetings, Sheree will follow up after the meeting with them.

If they decide not to attend our meetings, Frank and I will continue to reach out to them and offer support.

Advocacy

Frank and I would like to continue to promote Multiple Myeloma awareness. We would also like to make a greater effort to promote our support group. We are looking into the possibility of having hospitals or physicians treating newly diagnosed patients, to include our support group information in their new patient information packets. We would like to encourage all of you to speak to others about this disease. You will be surprised how many others know of someone with Multiple Myeloma. We would like to encourage you to talk about our support group to others...maybe in the waiting room before an appointment (even Hackensack...their support group meets during the day, and someone may be looking for an evening meeting. Many of our support group members are treated in Hackensack.)

Frank and I have been attending Pharmaceutical Informative Events, to promote and talk about our support group (the Pharma will usually have a table set up for us), and to tell the story of Frank's myeloma journey. This is a wonderful way to meet prospective members. We will let you know of any events of this kind are upcoming if anyone would like to join us.

Something New at Wednesday's Meeting?

- We are delaying the official start of the meeting to allow our attending members time to enjoy conversations with other members, and enjoy our refreshments (If a speaker is scheduled, this social time may be shortened). Now that we have an earlier start time (6:30 pm), please feel welcome to join us when you can.
- A star or heart sticker will now be affixed to your name tag to designate patient or caregiver
 - Patient - Star
 - Caregiver – Heart
- Steering Committee members will be wearing different lanyard name tags to distinguish us from the rest of the group in the

event you have a concern or question to discuss before or after a meeting

- Our “round table” discussions will now be referred to as “Sharing and Caring Time”. We would like to focus more on an update of how you are doing, rather than a complete medical history. This will hopefully allow time for everyone to speak.

An example of this format is...

“Name, year diagnosed, treatment you are currently on, and any updates on your health from our last discussion”

More time will be spent speaking with any new members that are in attendance, and any questions or concerns they may have.

News

The following upcoming events are available

On September 18, from 2:00 to 3:00PM, Rutgers Cancer Institute is presenting a program on Updates in Multiple Myeloma at the Institute in New Brunswick. More information can be found at <http://cinj.org/MultipleMyelomaSept18>

On September 20, October 4 and November 1, the Multiple Myeloma Research Foundation is continuing its Multiple Myeloma Webinar Series, Hot Topics in Multiple Myeloma. Subjects to be covered are: Minimal Residual Disease, Pros and Cons of Maintenance Therapy and Precision Medicine. More information can be found at <http://go.themmr.org/webmail/230662/37413985/bef9a50850c2c91c43013d8d3c0902c24dfbbeb04b8ce43ec9ccb18543a3dc6b>

On September 23, the 2017 Miracles for Myeloma 5K Run/Walk will be held at Oak Ridge Park in Clark, NJ. This is our Support Group's primary fund-raiser for the year and we need your support. More details and registration information can be found at <http://give.myeloma.org/Miracles2017>. Our Central Jersey Memorial Team is always one of the largest teams at the event and we hope to continue that representation again this year.

On September 24, from 9:00AM to Noon, the Leukemia & Lymphoma Society is sponsoring a program on Understanding Multiple Myeloma and Thriving After Diagnosis at the Holiday Inn of East Windsor. More information can be found at <http://bit.ly/MyelomaSept24>.

On September 30, the Myeloma Roundtable is sponsoring a program at Memorial Sloan Kettering Cancer Center in Manhattan on high-risk, relapsed and refractory disease. More information can be found at <https://www.myelomacrowd.org/september-30-2017-myeloma-crowd-round-tables-new-york-ny/>

On October 21, the Multiple Myeloma Research Foundation is sponsoring a 5K Run/Walk in Manhattan to raise money for multiple myeloma research. More information can be found at: <https://walkrun.themmr.org/new-york-city>

On November 3, the Multiple Myeloma Research Foundation is sponsoring a Patient Seminar at The Roosevelt Hotel in Manhattan. More information can be found at: www.themmr.org/nysummit.

Miracles for Myeloma

The Miracles for Myeloma 5K Walk/Run, which will be held on September 23, 2017 was discussed. This event is held at Oak Ridge Park, in Clark NJ and is a great fundraising event. (Please see link above for information). The support group is represented by the Central Jersey Memorial Team, but there is also Team Believe (Sheree/Ron Pask), and Team Cure! (Frank Morelli). Please consider attending this uplifting event, or donating to a

team. You could also donate a placard “In Honor Of” or “In Memory Of” someone, to be placed on the “Remembrance Path”.

Other News

We have created a list of area Multiple Myeloma Specialists. This list will be distributed to all new members in their “welcome” bags, but if anyone is interested in having the list emailed to them, please let us know.

Soon, Frank and my name’s and phone numbers will be added to the support group’s flyer, business cards, Web page, and Facebook page (Check out our web page at www.centralnj.support.myeloma.org)

One of our members spoke about the medical coverage for Vietnam Veterans who served at sea vs those on who served on the ground, and the exposure to Agent Orange.

Please visit www.bluewaternavy.org for more information. If you would like to see the benefits available to only those veterans who served on the ground, please visit

www.publichealth.va.gov/exposures/agentorange/conditions/multiple_myeloma.asp

Currently there are two bills being considered regarding this issue

HR 299 (House)

S. 422 (Senate)

Please take the time to contact your local representatives and tell them to support both these very important bills.

For Your Information

The following are online resources and blogs pertaining to Multiple Myeloma you may be interested in...

Myeloma Minute...www.myeloma.org/myeloma-minute

Smart Patients...www.smartpatients.com

Myeloma Crowd Radio...www.myelomacrowd.org/myeloma-crowd-radio

Myeloma Beacon...www.myelomabeacon.com

For forums to be sent to your email
www.myelomabeacon.com/forum/ucp.php?i=205

For myeloma news to be sent to email or to subscribe...
<http://www.myelomabeacon.com/email-subscription/>

One More Thing...

At our next meeting, we will have a speaker join us. Linda Schmidt, oncology nurse from Hackensack's John Theurer Cancer Center, will be speaking to us about "Myeloma 101" ...disease overview, treatments, etc. Linda will also answer any questions you may have regarding multiple myeloma. She currently also leads the Hackensack Support Group.

Be well,

Debbie Morelli

