

Recap of Central New Jersey Support Group Meeting

October 3, 2018

This meeting we were fortunate to have Holly Wall, Clinical Nurse Educator from Takeda Pharmaceutical Company, speak to the group about “Cancer Survivorship – Optimizing Your Wellness”. (Our previously scheduled speaker was unable to attend our meeting).

ANNOUNCEMENTS

After informing the group on upcoming events (noted in this email), I spoke to the group regarding our group’s privacy policies...

- When we send out group emails, all members will be BCC, (Blind Carbon Copied) with no email addresses showing.
- Our group will not share this group email list. The IMF does not have access to this list, nor do they ask for our membership list. It is for the use of this group only.
- Email addresses are not provided to other members. If you wish to email someone in our group, please contact us at the group email your request, we will then reach out to the person in question, and if they give us their permission we will provide the email addresses.
- Please feel free to share amongst yourselves your email addresses if you like.

MIRACLES FOR MYELOMA UPDATE...

Ron and Sheree Pask gave the group a Miracles for Myeloma update...

- 600 Participants registered for the Race
- Central Jersey Memorial Team (the main team for our support group) had the largest team with 52 participants
- Central Jersey Memorial Team also raised the most money...\$7170.00!
- 207 participants in the race were from our support group!
- The teams from our support including and in addition to Central Jersey Memorial Team raised \$20,650.00!!!

- As of October 3, over \$76,000.00 is raised, with monies being collected through the Miracles website open until December 2018.
- Next meeting Ron should have 2 videos from the race to share with us.

New Member

- We welcomed new member James to our group

Notes from Holly Wall's Presentation "Cancer Survivorship"

- Survivorship Care Plan
 - Three Stages
 - Acute Survivorship – Time of diagnosis/treatment
 - Extended Survivorship – Maintenance or no therapy
 - Permanent Survivorship – Long Term Remission
 - Needs are different in each phase
- Not all health care institutions have Survivorship Care Plans
- Included in Care Plans
 - Dieticians
 - Social Workers
 - Etc.
- These are part of Care Plans, but your health care institution may not refer to it as "Survivorship Care"
- You should always bring up to your health care provider you concern regarding
 - Your health
 - Psychological depression
 - Social challenges

- Etc.
- Multiple Myeloma can impact the caregiver too
 - Physical problems
 - Emotional problems
 - Financial problems
 - Etc.
- Financial Analysis
 - Good to have a discussion with your financial institution or financial planner at the time of your diagnosis
- Check with your health care institution as to whether or not they have a Survivorship Clinic or participate in a Survivorship Care Plan
- If not, create your own Care Plan
 - Collect Medical Information and Test Results
 - Blood test results, blood pressure readings, weight changes, M Spike or Light Chain changes
 - Create Goals – What Are They
 - Next trip you are looking forward to taking, upcoming weddings or celebrations, welcoming grandchildren
 - Take Control of Your Follow-Up Visits
 - Prepare questions for your health care provider...write them down before you meet with them
 - Log any changes about how you have been feeling and discuss with your health care provider
 - Bring a notebook with your questions and health observations and bring this to your follow-up visits...Take notes!

UPCOMING EVENTS AND NEWS

Register NOW for a Patient & Family Seminar in Philadelphia

Friday October 12 and Saturday October 13

<http://www.cvent.com/events/2018-imf-philadelphia-patient-family-seminar/event-summary-2de04d1a77a24853a769d448126c41f3.aspx?ct=8219faf0-1e56-47f4-89a0-260b9bc84eab>

If you find that 5K Walk/Runs appeal to you, you can join the Multiple Myeloma Research Foundation (“MMRF”) for their event in New York City on October 20th

<https://walkrun.themmr.org/newyorkcity18>

NEWS FROM THE IMF

“The Impact of Nutrition on Side Effect Management”

THURSDAY OCTOBER 4TH at 4:00 PM Pacific/5:00 PM Mountain/6:00 PM Central/7:00 PM Eastern [Register here!](#)

Ask Dr. Durie Video

- **September 6th: If you have myeloma, should undergo test for DNA sequencing? [Find out here.](#)**
- **September 13th: What is the latest on a new drug called Selinexor? [Find out here.](#)**

Dr. Durie’s Blog

- **September 20th: Myeloma Warrior spirit takes many forms! [Read about it here.](#)**

Myeloma Information

- September 6th: Blood cancer survivor to throw first pitch at Sept. 16th Houston Astros game. [Read here.](#)
- September 6th: Making Myeloma Matter! [Learn More.](#)
- September 7th: The IMF receives a 4-star rating from Charity Navigator. [Learn More.](#)
- September 10th: IMF announces all-star lineup for the 12th annual comedy celebration! [Learn More.](#)
- September 18th: Blood Cancer Awareness Month and baseball for myeloma: a huge success. [Learn More.](#)
- September 21st: Co-Pay assistance programs update (9/21/18). [Learn More.](#)
- September 21st: For Nurses: Keeping up with the latest in myeloma care. [Learn More.](#)
- October 4th: Living Well Teleconference: The impact of nutrition on side effect management. [Register here!](#)

Frequently Requested References

- How should patients eradicate or reduce diarrhea that may result from Revlimid treatment? [Find out here.](#)
- How can myeloma patients protect themselves from infections? [Find out here.](#)

MORE IMPORTANT INFORMATION

VAM Webinar on *Blue Water Navy Veterans Act of 2017*

https://register.gotowebinar.com/register/5192525419734002689?mc_cid=19ca38435a&mc_eid=c245a03d02

Karyopharm's Selinexor Demonstrates High Response Rates in Heavily-treated Multiple Myeloma Patients

<https://myelomaresearchnews.com/2018/09/28/selinexor-multiple-myeloma-patients-fares-well-storm-clinical-trial/>

New African American Multiple Myeloma Facebook Group

www.myelomacrowd.org/new-african-american-multiple-myeloma-facebook-group/?inf_contact_key=1f963fb9df96382a873def659afb5b536345f007800f5fa281549f91c8e3b5e7

CAR T-Cell

Clinical Trial: Study of CD8+ anti-BCMA CAR T-cells in Patients with Multiple Myeloma

www.myelomacrowd.org/clinical-trial-study-of-cd8-anti-bcma-car-t-cells-in-patients-with-multiple-myeloma/?inf_contact_key=c0fd143acc8cd5d563268bb45a2ec547e4eecd593b65ccf44a764f55b21e2ccb

CAR T Therapy Update by Edward Stadtmauer, MD, University of Pennsylvania

www.myelomacrowd.org/car-t-therapy-update-by-edward-stadtmauer-md-university-of-pennsylvania/?inf_contact_key=927ce5d4c5b6c94bf9ba4f88922cb630b5195927e681e621bae888cbabbcb9af

“Standing in the Gaap for African Americans With Multiple Myeloma”

“Celgene has created the “Standing in the Gaap for African Americans with Multiple Myeloma” initiative to help spread the word about how multiple myeloma affects African Americans differently, in order to improve the quality

of the care they receive.

www.myelomacentral.com/standing-in-the-gaap/what-is-standing-in-the-gaap/

Selective Digestive Decontamination May Reduce Risk of Infection In Myeloma Patients Undergoing Autologous Stem Cell Transplants

<https://myelomabeacon.org/news/2018/09/23/selective-digestive-decontamination-autologous-stem-cell-transplants/>

For More Information

Myeloma Research News

<https://myelomaresearchnews.com/>

Myeloma Crowd

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

The Myeloma Beacon

<https://myelomabeacon.org/>

International Myeloma Foundation

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

Myeloma Central

www.myelomacentral.com