

CENTRAL NJ MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR WEDNESDAY OCTOBER 4, 2017

Guest Speaker: Linda Schmidt, MM oncology nurse, specializing in MGUS at Hackensack University Medical Center/John Theurer Cancer Center, Hackensack University Medical Center Support Group
Facilitator

Linda Schmidt spoke to the group about many different Multiple Myeloma topics, as our members in attendance actively participated in a Q&A with her. Below are the interesting points from this meeting...

- The “Checkpoint Inhibitor (PD1/PDL1)” trials have been put on hold by the FDA. For more information, please see the below blog from Dr. Durie
www.myeloma.org/blog/dr-duries/further-fda-clinical-trial-holds-may-signal-end-checkpoint-inhibitors-myeloma
- A new trial may be in the works to break up Light Chains in the organs
- Now is the time to re-evaluate your health insurance, especially your supplemental plans
- If you are interested in obtaining diet health guidance from a dietician, Shop Rite grocery stores have a dietician on staff free of charge
- Robin Levy, Senior Director Public Policy and Advocacy, (rlevy@myeloma.org) is ...

“trying to locate a patient in Representative Lance’s District who would benefit from the federal oral parity legislation. Ideally, someone who is currently paying out of pocket for an oral anticancer medication.”

Oral Parity Legislation.... “The so-called "**oral chemotherapy parity laws**" — passed in 34 states plus the District of Columbia — require health insurers to cover **oral** chemotherapeutic agents under "no less favorable" terms than intravenous (IV) **chemotherapy**. The latter tends to be comprised of old drugs and is much less expensive. (Oct 2, 2014)”

Please contact Robin Levy at the above address, if you are interested.

- Myeloma Specialists – It is very important to have a Myeloma Specialist as part of your health care team. The specialist can coordinate with your local Oncologist/Hematologist, and should be the main physician following your disease and treatments. Myeloma Specialists may also have access to clinical trials should you wish to participate in one. Or you could research clinical trials available on your own as well.

Two members of your Steering Committee, Sheri Goldberg and Diane Kranz, have compiled a list of Myeloma Specialists in our area. Please respond to this email if you are interested in having the list emailed to you. Many thanks to Sheri and Diane for their hard work on compiling this list.

NEWS

The Miracles for Myeloma 5K Walk/Run was held at Oak Ridge Park, in Clark, NJ on Saturday September 23. As of today, October 11, over \$72,000 has been raised. The Miracles web site will be open if till December if you are interested in donating. Please visit

http://give.myeloma.org/site/TR?fr_id=1230&pg=entry#.WdzRqmhSw2w

You can also view video and pictures from this inspirational day. Five research grants have been awarded over the past five years because of this amazing fund raiser and we are hoping for a 6th!! Thanks to Sheree and Ron Pask for their passion and devotion to this event.

October 21, 2017 – 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>

November 3, 2017 – 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

November 11, 2017 – the Multiple Myeloma Research Foundation is sponsoring a 5K Run/Walk in Philadelphia. More information can be found at

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

Music and Myeloma – This information is from Myeloma Crowd Radio...

“For those of you who are music lovers, Takeda Oncology, along with a team of myeloma patients, has created a Spotify playlist to help support September’s blood Cancer Awareness Month. Takeda is partnering with the Myeloma Crowd organization for this project. The playlist is varied and contains inspiring music to represent our myeloma journey. For everyone who “follows” this playlist on Spotify, Takeda will donate to Myeloma Crowd. If you are interested in accessing the playlist, follow the link below within the note that the Myeloma Crowd has circulated. “

<https://open.spotify.com/user/music2fightmyeloma/playlist/3wulg899x69WFFfQ78AOTO>

You can also post a selfie on Instagram with the hashtag #music2fightmyeloma. Takeda will also donate \$5 to the Myeloma Crowd for each of these posts.

This is an informative site to visit

www.BMTinfonet.org - Blood and Marrow Transplant Information Network. Below is information regarding three videos regarding health insurance, employment, or financial issues after transplant.

<https://www.bmtinfonet.org/video/financial-health-after-transplant>

<https://www.bmtinfonet.org/video/employment-rights-and-disability-insurance>

<https://www.bmtinfonet.org/video/health-insurance-know-your-rights-and-options-0>

As fall begins its downward spiral towards winter, try to get out with family and friends and enjoy these beautiful days. Stay well all...

Debbie Morelli