

SUPPORT GROUP MEETING RECAP FOR MARCH 1, 2017

Speaker : Holly Wall, Takeda Clinical Oncology Nurse Educator

Ninlaro (ixazomib)

- Three fast facts
 - *Ninlaro is a proteasome inhibitor approved in 2015
 - *Four new therapies were approved 2015
 - *New criteria for Multiple Myeloma – SLIMCRAB
 - S – 60% or greater clonal plasma cells on bone marrow examination
 - Li – Light chain ratio of 100 or greater
 - M – MRI shows more than 1 focal lesion 5mm or larger
 - C – Calcium elevation in blood
 - R – Renal/Kidney involvement
 - A – Anemia
 - B - Destructive bone lesions
- Ninlaro is used in combination with Revlimid and Dex in patients who received one prior therapy
- You do not need to fail or relapse to take Ninlaro
- You see the most benefit when used in the beginning of the disease treatment.
- How Ninlaro works...

Ninlaro blocks the growth of myeloma cells by blocking the proteasomes in the cells which cause the myeloma cell to die.

- Possible Side Effects
 - *Low platelet count
 - *GI side effects – manageable with anti-diarrhea medications
 - *Neuropathy
 - *Swelling of the arms, hands, legs, etc.
 - *Skin reactions
- Ninlaro is a 4mg capsule that is the first and only proteasome inhibitor that you can take orally at home.
- You stay on Ninlaro until disease progression or unacceptable toxicity

Benefits

- Ninlaro helps patients with multiple myeloma live longer
- Ninlaro/Rev/Dex is proven to work in some patients whose multiple myeloma has come back or stopped responding to a prior therapy
- Ninlaro is proven to work quickly and effectively
- Ninlaro/Rev/Dex are all oral medications, which is convenient, and provide a great quality of life
- You can still take bisphosphonates while taking Ninlaro
- Ninlaro is taken once a week, 3 weeks on, 1 week off
- An average of 1.1 months after starting Ninlaro patients will see a response
- As long as you stay on Ninlaro, you will continue to respond

NOTE: This is a short summary of the presentation made at our meeting. You should check with your healthcare provider for more complete information on side effects and benefits in your particular situation.

Announcements

- Tonight, we welcomed 4 new Support Group members...Alan, Roger, Jim, and Stephanie (her father has MM)
- MAM Update
 - *Donate a photo phone app. 25 photos donated = 100 blood samples for myeloma research. As of March 1, 136 out of 1000 blood samples have been collected. 1566 people have donated 3416 photos!
 - *Courier News (Newspaper) has our press release, support group picture and information. To view on line visit mycentraljersey.com and search "myeloma", click on picture. You can also view it on the MAM.org website. Scroll to bottom to "News Articles", click "more" to read the article. This will also redirect you to the Courier News for the full article.
 - *Please send out physician letters (attached to last month's recap), post MAM fliers, Wear Your Myeloma Bracelets!, and Take Action! on the Myeloma Awareness Resolution <http://give.myeloma.org/site/PageNavigator/ActionCenter/Actioncenterhome.html>
 - *The Support Group mannequin challenge is posted on our Facebook page and on YouTube
 - *Our new Support Group business cards were distributed. Please remember to get some at the next meeting if you are interested.

Reminder

- Don't forget the IMF Patient & Family Seminar in Short Hills on April 7 & 8. You can register at shorthills2017.myeloma.org
- Please mark your calendars for the Miracles for Myeloma 5K Walk/Run 2017 to be held on Saturday September 23, 2017