

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP APRIL 4, 2018 MEETING RECAP

GUEST SPEAKER: Nicole Rode, a certified oncology nurse with 20+ years of oncology experience. She has been an oncology infusion nurse for most of her career. She obtained her nursing degree from Lancaster General Hospital School of Nursing and her Bachelor of Science Degree in Nursing from Drexel University. She has been a long-time member of the Oncology Nursing Society and has participated on advisory panels and speaker bureaus. Nicole is presently an Oncology Nurse Educator with Janssen Biotech.

TOPIC: Darzalex (Daratumumab), Dara

Below are a few facts on Dara, as presented by Nicole.

AS ALWAYS, PLEASE CONTACT YOUR HEALTH CARE PROVIDER FOR ADDITIONAL INFORMATION ON DARA, AS THIS IS ONLY A BRIEF SUMMARY

- Dara is a monoclonal antibody, which is administered by infusion
- Attaches to multiple myeloma cells directly killing them and/or allows the immune system to destroy them
- Targets and attaches to the protein called CD38, which is present on red blood cells and are present in high numbers on multiple myeloma cells. This may also affect other cells with CD38 on their surface
- Can affect blood tests to match your blood type. This can last up to 6 months after the final Dara infusion. Your

healthcare provider will do blood tests to match your blood type prior to Dara treatment

- Be sure to tell all healthcare providers that you are treating with Dara, especially before receiving blood transfusions
- Dara can decrease white blood counts, which help fight infections, and platelets which help blood clot
- Dara is given in combination with other multiple myeloma drugs, or as a single agent

TYPICAL INFUSION SCHEDULE

- First infusion is given over a long period of time (up to 7 hours), while you are checked for infusion related reactions. Subsequent infusions are given at a faster rate, or as per your healthcare provider
- Weeks 1-8 weekly infusions
- Weeks 9-24 bi-monthly infusions
- Weeks 25+ monthly infusions
- Given with premeds Dex, Benadryl, and Tylenol, or as per your healthcare provider
- The longer you can remain on Dara, the deeper your response

For questions on Dara treatment or for cost support options you can contact

Janssen Care Path

www.Janssencarepath.com/Darzalex

1-844-553-2792

SPRING CELEBRATION OF LIFE EVENT

Date: Wednesday May 2, 2018

Time: 6:00 pm – 8:00 pm

Place: Steeplechase Cancer Center, 3rd Floor Conference Room

As per your invitation, support group members, their families and friends are invited.

PLEASE RSVP BY WEDNESDAY APRIL 18, 2018 IF YOU WILL BE ATTENDING AND HOW MANY!!!

UPCOMING EVENTS:

April 16, 2018

Quad Treatment with Transplant for Newly Diagnosed Myeloma with Luciano Costa, MD, PhD University of Alabama

Monday, April 16, 2018 @ 10 am Pacific, 11 am Mountain, Noon Central, 1:00 pm Eastern

Call In by Phone to Listen Live: (347) 637-2631 or Listen Live Via Computer www.myelomacrowd.org/master-trial-costa/

April 28, 2018

Miles for Myeloma 5K Walk/Run Philadelphia, PA

http://give.myeloma.org/site/TR?fr_id=1500&pg=entry#.WsfKMIjwY2z

May 5, 2018

Myeloma Crowd Round Tables: New York, New York

www.myelomacrowd.org/may-5-2018-myeloma-crowd-round-tables-new-york-new-york/

Here is a copy of their email...

“Myeloma Crowd Round Tables, are day-long patient education meetings which are “graduate level,” for lack of a better term.

We will be holding one at the Irving Cancer Research Center on the campus of the Columbia University Medical Center on Saturday, May 5 from 9:15 am-3:30 pm, registration begins at 8:30 am.

Should anyone need financial assistance, we can waive the \$25 registration fee. We will also be providing free parking, lunch and refreshments. We don't want cost to be an obstacle to keep anyone who wants to from attending.

Over the past two years we have held 14 Round Tables. Each one focuses on the strengths of the faculty and addresses the complicated questions in myeloma treatment and research including topics like myeloma genetics and genomics, imaging, combination therapies, the role of transplantation, and cutting-edge issues like CAR T cells and vaccines. One of the comments from our most recent Round Table in Baltimore sums it up well: "This was not 'Myeloma 101' - it was very advanced/complex...I would definitely attend another one, and they have one planned for NY on May 5."

May 9, 2018

9/11 HEALTH AND COMPENSATION PRESENTATION HOSTED BY THE
STATEN ISLAND MYELOMA SUPPORT GROUP

www.myeloma.org/article/911-health-and-compensation-presentation-hosted-staten-island-myeloma-support-group

INFORMATION:

New Myeloma Test Developed by the MMRF and Collaborators at Washington University St. Louis Can Help Determine Risk and Prognosis with More Sensitivity Than Current Methods

By Mary DeRome, Director of Medical Communications and Education at MMRF

www.themmr.org/new-myeloma-test-developed-mmr-collaborators-washington-university-st-louis-can-help-determine-risk-prognosis-sensitivity-current-methods/

A STEP TOWARD PRECISION MEDICINE

WRITTEN BY: BRIAN GM DURIE MD

www.myeloma.org/blog/dr-duries/step-toward-precision-medicine

ABBVIE AND IMF ANNOUNCE PARTNERSHIP TO STUDY THE ROLE OF A GENETIC MUTATION IN OUTCOMES OF PATIENTS WITH MULTIPLE MYELOMA

www.myeloma.org/article/abbvie-and-imf-announce-partnership-study-role-genetic-mutation-outcomes-patients-multiple

ACCoRd Trial to Test Ninlaro Treatment for ASCT-Relapsed Multiple Myeloma

www.myelomaresearchnews.com/2018/03/28/accord-trial-test-treatment-asct-relapsed-multiple-myeloma/

Enhancing Myeloma Knowledge and Access to Latest Treatments in African American Communities

<http://www.lls.org/myeloma-link>

TOXIC EXPOSURES UNLEASHED

WRITTEN BY: BRIAN GM DURIE MD

www.myeloma.org/blog/dr-duries/toxic-exposures-unleashed

Researchers Suggest Increased Screening of MGUS Patients to Prevent Multiple Myeloma

www.myelomacrowd.org/myeloma-screening/

VETERANS AGAINST MYELOMA

<http://veterans.myeloma.org/>

Right-to-Try Bill Moves Forward

The Right-to-Try bill recently passed in the United States House of Representatives

www.curetoday.com/articles/right-to-try-bill-moves-forward

IMF's Grassroots FUNdraising Program

www.myeloma.org/member-fundraiser

ASK DR. DURIE VIDEOS:

WHAT SHOULD PATIENTS DO IF THEIR DOCTOR IS UNSURE IF THEY HAVE SMOLDERING OR ACTIVE MYELOMA?

www.myeloma.org/videos/what-should-patients-do-if-their-doctor-unsure-if-they-have-smoldering-or-active-myeloma-0

WHAT SUPPLEMENTS, IF ANY, SHOULD A MYELOMA PATIENT TAKE?

www.myeloma.org/videos/what-supplements-if-any-should-myeloma-patient-take-0

WHAT IMPACT DO REVLIMID® (LENALIDOMIDE) AND POMALYST® (POMALIDOMIDE) HAVE ON THE BONE MARROW?

www.myeloma.org/videos/what-impact-do-revlimid-lenalidomide-and-pomalyst-pomalidomide-have-bone-marrow-0

BEST OPTIONS FOR EARLY RELAPSE AFTER UNDERGOING VRD THERAPY WITH STEM CELL TRANSPLANT

<https://www.myeloma.org/videos/best-options-early-relapse-after-undergoing-vrd-therapy-stem-cell-transplant-0>

ATTENTION!!

Our support group member, Richard Poznansky, is looking for Veterans who were involved with live warhead assembly and have multiple myeloma, and were stationed at the Killeen Base, in Texas during the late 1950's/60's.

Please contact Richard at rwpox@verizon.net

Hope to see many of you at our upcoming Spring Celebration of Life Event, and we are hoping mother nature will cooperate, and it will indeed finally feel like spring. Stay well,

Debbie Morelli