

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP MEETING RECAP FOR MARCH 6, 2019

Speaker: Holly Wall, RN, MSN, ACNP

Clinical Nurse Educator, from Takeda Pharmaceutical

Topic: Understanding Lab Values

Once again, we were fortunate to have Holly Wall, Clinical Nurse Educator from Takeda speak to the group. As always, Holly's presentation was very informative and the group engaged in meaningful discussion with her on Lab Values as well as other topics.

As there was too much information presented for me to recap, you can visit the IMF website and download the booklet Understanding Test Results. www.myeloma.org/cancer-information-series

You can find it on page 3.

We welcomed one new member, and have 2 additional new members now on our email list.

UPCOMING EVENTS:

International Myeloma Foundation Patient/Family Seminar

When: Friday, April 5, 2019 - Saturday, April 6, 2019

Where: Hilton Short Hills

41 JFK Parkway

www.myeloma.org/events/2019-patient-family-seminar-short-hills-nj

Visit to register

Spring Celebration of Life Event

When: May 1, 2019

Where: Steeplechase Cancer Center, 3rd Floor Conference Room

Our group's Spring Celebration of Life Event will soon be here! In place of our regular support group meeting, we will be meeting upstairs for an evening of delicious catered food and friendly conversations. Your family and close friends are also invited to attend. A formal email invitation with all of the details will be sent out in April. This social event is provided to you free of charge courtesy of grants and donations received. Our grant application from Celgene is still being considered, so we are hopeful they will be able to support our event again this year. **If anyone has a friendly relationship with a restaurant, who may be willing to donate a prepared dish, please let me know.** In the event we do not receive the full amount requested from Celgene, these donations will allow us to have an event with more food options. (Non-profit paperwork available upon request)

MYELOMA ACTION MONTH

VIDEO

I would like to thank everyone who participated in our Myeloma Action Month, "Myeloma Warriors" video. Everyone had such heartfelt comments! Thank you again to Ron and Sheree Pask for making the "frame" we all made our comments inside, and to Ron for taking the video of each of us, and editing it into the finished product. You can view the video here

IMF YouTube - https://youtu.be/dL_W-LXb7k

MAM.myeloma.org - <http://mam.myeloma.org/be-a-warrior/>

PRESS RELEASE

I posted a MAM press release, that also has a section written up about our support group. You can view it here (the press release is provided by the IMF...I provided the Support Group write-up)

Bridgewater Patch - <https://patch.com/new-jersey/bridgewater/march-myeloma-action-month>

It was also published in our local paper, the Observer Tribune and in the Somerville Times.

DONATE YOUR BIRTHDAY

During the month of March 2019, Janssen Oncology will match up to \$10,000 of Facebook Birthday donations benefiting the International Myeloma Foundation. Donating your birthday is one of the simplest ways to kick off your own fundraiser benefiting the IMF. Just think, every dollar you raise for the IMF can be doubled! Visit the site to learn how!

<http://mam.myeloma.org/donate-your-birthday/>

ATTENTION VETERANS!!!

Blue Water Navy Vietnam Veterans Handed Court Victory

“On Tuesday, January 29th the U.S. Court of Appeals for the Federal Circuit in Washington, D.C. [decided a case](#) that restores a presumption of exposure to the chemicals collectively known as Agent Orange for veterans who served off the coast of Vietnam during the war. The case, *Procopio v. Wilkie*, reverses the courts own ruling from 2006 in *Haas v. Peake* that erroneously excluded Blue Water Navy Vietnam Veterans from the *Agent Orange Act of 1991*. That case sided with a Department of Veteran Affairs (VA) reading of the Act by interpreting “service in the Republic of Vietnam” to narrowly mean only on the land mass of the country or its inland waterways. *Procopio* holds that it was the intent of Congress to include Blue Water Veterans under the *Agent Orange Act* and that the VA erred in its interpretation.

Blue Water Navy Vietnam Veterans now have the same presumption of exposure as any other Vietnam Veteran who served between January 9, 1962 and May 7, 1975. The presumption of exposure makes it much easier for veterans to make a claim for benefits, as they no longer must definitively prove they came into contact with Agent Orange if they developed one of the diseases recognized to be caused by exposure. Myeloma is one of those [recognized diseases](#).

While this is fantastic news for the estimated 60,000 Blue Water Navy Vietnam Veterans affected by the courts ruling, it's still important that this benefit be legislatively reinforced as the VA may choose to appeal *Procopio* to the Supreme Court. With the new Congress, a new *Blue Water Navy Vietnam Veterans Act* ([H.R. 299](#)) has been reintroduced in the House. We urge you to [contact your Representative](#) and ask them to support this bill.”

YEAR AT A GLANCE

April – Open meeting

May – Spring Celebration of Life Event

June – Dr. Biran, Multiple Myeloma Specialist from Hackensack University Medical Center - Speaker

July – No meeting

August –

September – Kelley Sidorowicz, Regional Director, Support Groups, IMF - Speaker

Miracles for Myeloma 5K Run/Walk Fundraiser, September 21, 2019

October -

November -

December -

We are in the process of contacting additional speakers!

IMPORTANT INFORMATION AND LINKS

IMF

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

IMF TV

www.myeloma.org/imf-tv

- Is there a link between MGUS and kidney damage in myeloma patients?
- Is Daratumumab Being Used in the Frontline Setting for Myeloma Patients?
- Is the combination of Velcade, Revlimid, and dexamethasone (VRd) helpful for myeloma patients over the age of 65?
- What is a BiTE and how likely is it to help me to achieve a response and remission for my myeloma?
- Do I Need A Transplant

Managing Complications and Side Effects

www.myeloma.org/multiple-myeloma-complications

Caregiver Resources

www.myeloma.org/resources-support/caregiver-resources

MMRF

<https://themmrf.org>

Patient Power

www.patientpower.info/multiple-myeloma

Strengthening your Medical Team: Benefits of Connecting with a Myeloma Dietician

www.patientpower.info/en/video/strengthening-your-medical-team-benefits-of-connecting-with-a-myeloma-dietician

Hope and Progress in CAR-T Cell Therapy for Myeloma

www.patientpower.info/video/hope-and-progress-in-car-t-cell-therapy-for-myeloma?autoplay=1

Cure

www.curetoday.com/tumor/myeloma

Topline Results Support Quicker, Convenient Administration of Darzalex in Myeloma Therapy (subcutaneous injections of Darzalex)

www.curetoday.com/articles/topline-results-support-quicker-convenient-administration-of-darzalex-in-myeloma-therapy

FDA Advisory Committee Votes Against Accelerated Approval of Selinexor for Multiple Myeloma

www.curetoday.com/articles/fda-advisory-committee-votes-against-accelerated-approval-of-selinexor-for-multiple-myeloma

Myeloma Crowd

www.myelomacrowd.org

www.myelomacrowd.org/myeloma-news/

- **Obesity Is On The Rise, And So Is Cancer**
- **Being Minimal Residual Disease Negative Before Or After Transplant Means Better Overall Survival For Myeloma Patients**
- **Strategies To Overcome Car T Cell Exhaustion In Multiple Myeloma**
- **Clinical Trial Car T Coverage For Medicare/Medicaid Multiple Myeloma Patients Proposed**

Myeloma Crowd Radio

www.myelomacrowd.org/myelomacrowd-radio/

- **Full Show: A New Cd38 Monoclonal Antibody Called Isatuximab Gets Closer To The Clinic, With Ravi Vij, Md, Washington University**

Myeloma Research News

<https://myelomaresearchnews.com/>

- **Once-weekly Kyprolis Safe, Effective for Untreated Multiple Myeloma Patients, Study Finds**
- **Gamida, Editas Partner to Create Genetically Engineered NAM-NK Cells for Treating Blood, Solid Cancers**
- **Ninlaro Maintenance Delays Disease Progression, Death in Myeloma Patients, Phase 3 Trial Shows**

Myeloma Beacon

<https://myelomabeacon.org/>

OncLive.com

<https://www.onclive.com/specialty/myeloma>

videos and articles

Managing Myeloma

<http://www.managingmyeloma.com/>

- **What factors do you consider when choosing treatment in newly diagnosed multiple myeloma?**

Myeloma Explained.com

www.myelomaexplained.com

Hope to see you in April. Spring is in the air!! Stay well...

Debbie Morelli