

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP VIRTUAL MEETING DECEMBER 2, 2020 RECAP**

**There were 36 members in attendance**

**Guest Speaker: Kelley Sidorowicz, Director of Support Groups,  
International Myeloma Foundation**

Kelley spoke to group on many topics including trial and drug updates, the IMF and their Advocacy Program, IMF Podcasts, how to follow ASH 2020 on the IMF website, to name a few.

On November 30, 2020, Frank and I participated in a Support Group Leaders call with other support group leaders from around the country. The guest speaker was Chad Seward, Senior Director Advocacy, Hematology Bristol Myers Squibb. Below are some important and informative takeaways from that meeting.

- Bristol Myers Squibb (BMS) (recently acquired Celgene Pharmaceutical) drugs for Multiple Myeloma
  - Revlimid (REV) (Lenalidomide)
  - Pomalyst (POM) (Pomalidomide)
  - Empliciti (ELO) (Elotuzumab)
    - REMS Companion App for smartphone...allows for patients to take the REV, POM, ELO survey on their

phone rather than on a phone call with call center prior to medication being dispensed

- BMS response to COVID-19
  - Emergency Food Assistance Program – for food delivery to patients with COVID-19
  - No cost for medicines from BMS if job is lost due to COVID-19
- Survivorship Today Program
  - “An initiative by Bristol Myers Squibb, Survivorship Today aims to share stories of people across the country who have been affected by cancer and advance our collective understanding of what it's like to live with the disease today”. Short videos
- Reflection Ambassador Program
  - “Ambassador” speaks about his/her journey on Revlimid to support groups
- Exciting Myeloma Drug News
  - BB2121 – CAR T-Cell therapy to be approved for MM in 2021
  - CELMoD – CAR T-Cell therapy in pill form – in trials now
- Celgene Patient Support will transition to BMS Access Support

At last month’s virtual meeting, our guest speaker was Brian McMahon of Spark Cures. (Four-time caregiver and founder). Spark Cures was created to help myeloma patients find, understand, and connect with

eligible clinical trials around the US. Brian was kind enough to share his slides from last month's presentation. Please follow the link below...

<https://www.dropbox.com/s/ybm4po967hizgz1/2020-09%20-%20Support%20Group%20Presentation.pdf?dl=0>

**CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP  
VIRTUAL MEETING RECAP DECEMBER 2, 2020  
INFORMATIONAL MYELOMA LINKS**

**International Myeloma Foundation (IMF)**

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

- IMF at ASH 2020
  - ASH 2020: Building Toward the Future of Myeloma Care
  - IMF Support Group Leaders at ASH
  - ASH 2020 Video Library
- Telehealth - How to Make the Most of Your Healthcare Provider Visit (Replay)
- IMF News
  - Give with Bing
    - You can help fund \$1,000,000.00 in donations for Brian Novis Research Grant Awards given by the International Myeloma Foundation

- Charity Navigator Awards IMF a 4-Star Rating for the 16th Time
- Co-pay Assistance Programs Update (12/3/2020)
- Ask Dr. Durie
  - What does the approval of Darzalex Faspro™ mean for myeloma patients?
  - COVID-19 FAQ #24: For myeloma patients, how important is it to wear a mask?
- IMF Infoline - 800-452-2873 or at [infoline@myeloma.org](mailto:infoline@myeloma.org)
  - “With a focus on the health and well-being of our staff given the growing concerns over the COVID-19 (coronavirus), the IMF’s physical offices will close...with a reopen date to be determined. During this time, we recommend if you have questions for the InfoLine, please leave a message at 1-800-452-2873 or at [infoline@myeloma.org](mailto:infoline@myeloma.org). We will not be able to respond in real-time, but we will get back to all inquiries in the order they have been received”

## **The Multiple Myeloma Research Foundation (MMRF)**

<https://themmrf.org>

- ASH 2020 Blogs
- Multiple Myeloma Research Foundation and Dana-Farber Cancer Institute Announce Groundbreaking Collaboration to Advance Progress for Smoldering Multiple Myeloma Patients
- The MMRF Drives Unparalleled Advances for Multiple Myeloma Patients

- Participate in the MMRF CureCloud
  - The MMRF CureCloud® is a research study that includes the first at-home genomic testing program. This comprehensive data hub of clinical and genomic information can help researchers, clinicians and patients make smarter treatment decisions

## **Myeloma Crowd**

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

- December 19, 2020 12:00 pm EDT
  - Side Effects of Myeloma Treatment: Register Now for the Myeloma Crowd Round Table Interactive Webcast
- ASH 2020: Myeloma Experts Debate Duration of Maintenance Therapy
- ASH 2020: The Race for a Multiple Myeloma Bi-Specific Antibody
- ASH 2020: Data Supports Transplant As Backbone of Therapy in Myeloma, or Does It?
- ASH 2020: Managing CAR T Side Effects in Multiple Myeloma
- ASH 2020: Turning Hope into Reality - What to Know and What to Do!
- ASH 2020: Real World Use of Minimal Residual Disease (MRD) Testing in Multiple Myeloma
- FDA Removes Clinical Trial Hold on Cellectis Off-the-Shelf CAR T for Multiple Myeloma

- Belantamab Mafodotin Teams with SpringWorks Drug to Increase BCMA Expression in Early Myeloma Trial
- Myeloma Clinical Trials Explained: CLR-131
- What to Ask Your Doctor at Your First Multiple Myeloma Appointment
- How Pomalidomide Works to Kill Multiple Myeloma
- Response Definitions After Myeloma Treatment
- Care for the Caregiver
- HealthTree University: Autologous Stem Cell Transplant (Part 3 of 3)
- HealthTree University: Precursor Conditions (Part 1 of 3 - MGUS)
- HealthTree University: Precursor Conditions (Part 2 of 3 - SMM)
- Myeloma Crowd
- Research Initiative
- The Myeloma Crowd Research Initiative (MCRI) is a new approach to funding cancer research; combining the skill and knowledge of leading myeloma specialists with the patient perspective and supportive patient social communities to select and fund promising research projects in myeloma. The goal of the MCRI is to find and fund a cure for multiple myeloma.
  - Creating a Myeloma Patient Immune System Signature
  - Testing Your Individual Myeloma Tumor Against Available Myeloma Therapies
  - Targeting CD24 to Eliminate Myeloma Stem Cells
  - Car T-cell Therapy Targeting CS1 & BCMA

- T-cell Therapy with Autologous Transplant
- MCRT Webcast: Making Sense of Myeloma Bone Issues (replay)

## Myeloma Beacon

<https://myelomabeacon.org>

- Press Releases
  - **Breckenridge Announces Final Approval Of Its ANDA For Pomalidomide Capsules (Generic For Pomalyst)**
  - FDA Lifts Clinical Hold On MELANI-01 Study Evaluating Cellectis' Product Candidate UCARTCS1 In Multiple Myeloma
  - Janssen Submits Applications In U.S. And EU Seeking Approval of Darzalex Faspro (Daratumumab And Hyaluronidase-fihj) / Darzalex (Daratumumab) Subcutaneous (SC) Formulation In Combination With Pomalidomide And Dexamethasone For Patients With Relapsed Or Refractory Multiple Myeloma
  - XNK Therapeutics Receives US Orphan Drug Status For NK Cell-Based Immunotherapy In Multiple Myeloma

## Cure

<https://www2.curetoday.com/tumor/myeloma>

- Venclexta With Velcade and Dexamethasone May Improve Progression-Free Survival in Relapsed or Refractory Multiple Myeloma
- Evolving Standards and Heated Debates in the Treatment of Newly Diagnosed Multiple Myeloma

## **Myeloma Research News**

<https://myelomaresearchnews.com/>

- FDA Lifts Hold on Phase 1 Trial for Car-T-Cell Therapy UCARTCS1A
- New \$100M Program Aims to Improve Diversity in Clinical Trials
- Approval of Injection Darzalex Combo for Advanced Myeloma Sought in US, EU
- Allogene to Present Positive Phase 1 Data for Investigational CAR T-cell Therapy ALLO-715

## **Patient Power**

<https://patientpower.info/multiple-myeloma/>

- Is Stem Cell Transplant Best for Relapsed Myeloma Patients?
- ASH 2020 Multiple Myeloma Daily Wrap-Up: New Treatments & Hope
- Multiple Myeloma Patient Story: Finding Hope After Diagnosis
- Doctor Explains Multiple Myeloma Diagnosis and Next Steps



- What New Myeloma Drugs Are Available?
- You Have Multiple Myeloma, Now What?
- And, more!

## **Myeloma Hub**

<https://multiplemyelomahub.com/>

- ASH 2020
- Editorial theme | Incidence and diagnosis of AL amyloidosis
- Is re-treatment possible with anti-CD38 therapies?

## **ASH Clinical News**

<https://www.ashclinicalnews.org/?s=multiple+Myeloma>

- FDA Lifts Clinical Hold on Study Evaluating UCARTCS1 for Multiple Myeloma
- Alfred Garfall: Evaluating Teclistamab in Relapsed and/or Refractory Multiple Myeloma
- NK Cell Therapy Receives Orphan Drug Designation for Multiple Myeloma

## **ASH**

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

## HealthTree University Myeloma

<https://www.youtube.com/channel/UC27i8v856WBGy-4ONPJS0MQ>

- Lots of great, short, informative myeloma videos

## CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP VIRTUAL MEETING RECAP FOR DECEMBER 2, 2020 COVID/MULTIPLE MYELOMA INFORMATIONAL LINKS

## Myeloma Research News

<https://myelomaresearchnews.com/>

### **TRIAL ENROLLMENT NEEDED! Dana-Farber, Quest Diagnostics Studying COVID-19 Prevalence in Myeloma**

- **The aim of the Immune Profiling with Antibody-based COVID-19 Testing study, or IMPACT, is to understand what happens to the immune system during a COVID-19 infection in people with multiple myeloma or myeloma precursor conditions.**
- **“This study is critical to arm medical professionals with important information and guidance on how to proceed when treating patients with MGUS and smoldering multiple myeloma during the pandemic,” Irene Ghobrial, MD, a senior physician at Dana-Farber, said in a press release.**

- **Up to 1,000 participants can enroll in the IMPACT study through the ongoing PROMISE and PCROWD studies.**
- **More information and a free screening can be obtained through [www.theimpactstudy.org](http://www.theimpactstudy.org) or by calling 617-582-8544.**

## **International Myeloma Foundation**

<https://www.myeloma.org/covid19-myeloma-patients>

- Science Leads the Way in Treatment of Myeloma and COVID-19
- Staying Positive and Strong in Times of Crisis: A Prescription for Resilience
- #ASKDRDURIE COVID-19 FAQs
- Federal Government Response to COVID-19
- COVID-19 External Resources
- Pharma Resources

## **The Multiple Myeloma Research Foundation**

<https://themmrf.org/2020/04/14/multiple-myeloma-covid-19-guidelines-for-health-care-providers/>

- Multiple Myeloma & COVID-19 Guidelines for Health Care Providers
  - General practice guidelines
  - Therapy Options for Myeloma Patients
  - Transplant and cellular (CAR T-cell) therapy

- Clinical trials
- Resources

## **Myeloma Crowd**

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

- ASH 2020: Dr. Fauci Opens with Reflections on COVID-19
- COVID-19 Isolation Precautions for Immunocompromised Patients

## **Myeloma Crowd Radio**

<https://www.myelomacrowd.org/myeloma-crowd-radio-episodes/>

- Mortality of Hospitalized Multiple Myeloma Patients Diagnosed with a COVID-19 Infection

## **Cure**

<https://www2.curetoday.com/search?searchTerm=covid>

- Cancer, Boundaries, Safety and COVID-19 Considerations During the Holidays

## **Patient Power**

<https://patientpower.info/search/?center=&query=coronavirus>

- First Clinical Trial for Blood Cancer Patients with COVID-19
- Stem Cell Transplant Expert Talks Recovery & COVID Vaccine

## **Leukemia & Lymphoma Society (LLS)**

[https://www.lls.org/llssearch?search-terms=covid&search\\_language=en](https://www.lls.org/llssearch?search-terms=covid&search_language=en)

- LLS COVID-19 Patient Financial Aid Program
- LLS Answers 10 Questions About Covid-19 Vaccines