

CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP

JUNE UPDATE

REMINDER!! WE WILL BE NOT BE HAVING A SUPPORT GROUP MEETING FOR JULY, VIRTUAL OR IN-PERSON.

Our June meeting was our second virtual meeting via Zoom. There were 39 members in attendance and four guest speakers. We were fortunate to be joined by guest speakers from the Multiple Myeloma Research Foundation...

Mary DeRome – Mary is the Director Of Medical Communications and Education

Sarah Coulter, RN, OCN – Sarah is a registered nurse specializing in Hematology Oncology and Bone Marrow Transplant.

Erin Menshing, RN, BSN, BA – Erin is a registered Oncology nurse.

Brian Hochberg – is a Senior Manager, Development

You can get in touch with them at should you have any questions or concerns.

Their number is 888-841-6673

Their email address is patientnavigator@themmrf.org

After spending a few moments speaking about the history of the MMRF, and the timeline for the important programs the MMRF is involved in,

the remainder of the meeting was spent with our speakers discussing five of the many programs of the MMRF is focusing on today.

- The MMRF CoMMpass Study
- MyDrug
- Right Track
- Myeloma Mentors Program
- The MMRF Cure Cloud

UPCOMING EVENT:

Post ASCO and EHA 2020 Free Webinar

<https://www.myeloma.org/videos/post-asco-eha-2020>

June 25, 2020

4:00 PM ET

“Learn more about current trends in myeloma treatment and research with this update from two major medical meetings held virtually in May and June 2020.”

Speakers/Panel:

Dr. Brian G.M. Durie, Dr. Joseph Mikhael, Dr. Craig Cole

Dr. Brian G.M. Durie will explain what’s new and exciting from:

- American Society of Clinical Oncology (ASCO) Virtual Scientific Program - May 29-31, 2020
- European Hematology Association (EHA) Virtual Congress - June 11-14, 2020

MARK YOUR CALENDARS!!

8th Annual Miracles for Myeloma 5K Run/Walk – VIRTUAL EDITION

http://give.myeloma.org/site/TR?fr_id=2101&pg=entry

“...8th Annual **Miracles for Myeloma 5K Run/Walk: Virtual Edition** will take place on Saturday, September 26, 2020! ...1st ever Virtual Experience! Due to the present pandemic, we will be transitioning the 5K to a virtual experience as well as opening up registration to participants around the world...”

You can create your own team, participate as an individual, honor/remember someone on the virtual “Remembrance Path” and view this touching and inspiring part of Miracles, or join the Central Jersey Memorial Team. (Check the Miracles website for updates on this team.)

IMPORTANT INFORMATION:

Myeloma Crowd

<https://www.myelomacrowd.org/karyopharm-donates-free-masks-for-multiple-myeloma-and-other-patients/>

- Karyopharm Donates Free Masks for Multiple Myeloma and Other Patients

Leukemia/Lymphoma Society (LLS)

<https://www.lls.org/support/financial-support/covid-19-patient-financial-aid-program>

- LLS COVID-19 PATIENT FINANCIAL AID Program

OncoLink

<https://www.oncolink.org/support/resources/coping-with-covid-19/covid-19-emergency-financial-assistance-for-people-with-cancer>

- COVID-19 Emergency Financial Assistance for People with Cancer

Myeloma Crowd

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

- Finding Financial Resources for Insurance and Prescription Medication Costs with impact of COVID-19

Our next meeting will be an open virtual meeting on August 5, 2020 at 6:30 pm, via Zoom. As there will be no “Informational Links” sent to you for July, all the web pages from previous “Informational Links” can be trusted with accurate information, should you wish to visit those sites in July on your own.

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INFORMATIONAL MYELOMA LINKS

International Myeloma Foundation (IMF)

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

- Co-pay Assistance Programs Update (6/11/2020)
- Week in Review by Dr. Brian Durie
 - Truth and Consequences in the Time of Racism and COVID-19
 - The Pandemic, National Crises, and Racial Health Disparities
 - Virtual ASCO and a Real Pandemic
 - Patient Safety More Important Than Ever As States Begin to Reopen: COVID-19 UPDATE
 - COVID-19 Update: TRUTH, TESTING, AND THE FUTURE
 - Re-Focusing on Myeloma Care in a COVID-19 World
- Let Your Voice Be Heard Through Advocacy

The Multiple Myeloma Research Foundation (MMRF)

<https://themmrf.org/>

Myeloma Crowd

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

- EHA Interactive Myeloma Crowd Round Table Webcast with Three Myeloma Experts:
 - Highlights of the European Hematology Association Annual Congress with Three European Myeloma Experts

- June 20 @ Noon - 1:30 pm Eastern
- Financial Resources
 - <https://www.myelomacrowd.org/financial-helpful-resources/>
- ASCO 2020: High-Risk Disease Progress Continues Despite Uncertainties
- Karyopharm Donates Free Masks for Multiple Myeloma and Other Patients
 - <https://www.myelomacrowd.org/karyopharm-donates-free-masks-for-multiple-myeloma-and-other-patients/>
- ASCO 2020: Genetics Predict Smoldering Myeloma Progression
- HealthTree University: Multiple Myeloma Basics Part 1 (1 of 3)
- HealthTree University: Multiple Myeloma Basics Part 1 (2 of 3)
- Myeloma Clinical Trials Explained: CLR-131
- Myeloma Crowd Round Table, From May 16 Webcast Expert Videos – Part 1: Newly Diagnosed Multiple Myeloma
- Myeloma Crowd Round Table, From May 16 Webcast Expert Videos – Part 2: Relapsed/Refractory Multiple Myeloma, Amyloidosis
- ASCO 2020: KRD vs. VRD for Newly Diagnosed Multiple Myeloma
- ASCO 2020: Mass Spectrometry in MRD Assessment
- ASCO 2020: Various Approaches for Smoldering Myeloma
- ASCO 2020: Are Myeloma Patients Getting the Right Vaccinations?

- XPOVIO (selinexor) Study Shows Impact When Used in Earlier Lines of Multiple Myeloma Therapy with Velcade and Dex
- Diet Can Affect the Impact and Potency of Chemotherapy

Myeloma Crowd Radio

<https://www.blogtalkradio.com/myelomacrowdradio>

Cure

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

- First-in-Human Trial of Novel Therapy Shows Promising Results in Relapsed/Refractory Multiple Myeloma
- Adding Xpovio to Standard Drugs for Multiple Myeloma Delays Disease Progression and Reduces Neuropathy
- Standard of Care in Newly Diagnosed Myeloma Remains as Carfilzomib Triplet Does Not Improve Outcomes

OnLive

<https://www.onlive.com/clinical/multiple-myeloma>

- Dr. Berdeja on Updated CARTITUDE-1 Results With JNJ-4258 in Multiple Myeloma
- Dr. Weitzman on Sequencing Challenges in Myeloma Treatment
- Dr. Davies on Personalizing Treatment in Relapsed/Refractory Myeloma

- Dr. Mateos on the Ongoing CANOVA Trial in t(11;14) Multiple Myeloma
- Dr. Dimopoulos on the Evolution of Selinexor in Multiple Myeloma
- Dr. Richardson on the Mechanism of Action of CC-92480 in Multiple Myeloma

Myeloma Research News

<https://myelomaresearchnews.com/>

- Xpovio Triple Combo Before FDA for Previously Treated Myeloma Patients
- FDA Asks for More Data on Ide-cel as Potential Multiple Myeloma Therapy
- Cell Protein Analysis May Predict Multiple Myeloma Response to Treatment

Patient Power

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

- CAR T-Cell Clinical Trial Updates for Myeloma Patients\
- What Does the StaMINA Trial Mean for Myeloma Patients?
- What Does the ENDURANCE Trial Mean for Myeloma Patients?
- Exciting Advances in Treating Multiple Myeloma
- Creating Your Myeloma Treatment Path and Factors to Consider

- Multiple Myeloma Patients Discuss Support and Survivorship
- Multiple Myeloma Research Foundation Launches Patient Registry
- Multiple Myeloma Support Resources

HealthTree University – YouTube

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

- What are lytic and focal bone lesions and how common are they?
- What imaging is used at diagnosis to detect myeloma bone disease?
- What is a plasmacytoma?
- How is active myeloma defined?

Clinical Care Options-Oncology

<https://www.clinicaloptions.com/oncology?Topics=e33fdf681f1d47b79d7b84449a03ff66&q&sortBy&sortOrder=asc&page=1>

- This web site was referred to us by the Boca Raton Multiple Myeloma Support Group. There are too many topics to list...check it out!

Leukemia/Lymphoma Society (LLS)

<https://www.lls.org/blog/working-with-lawmakers-to-address-the-unique-needs-of-cancer-patients>

- Working With Lawmakers To Address The Unique Needs Of Cancer Patients

Current and Emerging Trends in Multiple Myeloma

<https://event.on24.com/eventRegistration/EventLobbyServlet?target=reg20.jsp&referrer=https://wcc.on24.com/webcast/groupregistration/2396919&eventid=2396919&sessionid=1&key=9B1026854555C978083628352492D351®Tag=1011513&sourcepage=register>

Myeloma Central

<https://www.myelomacentral.com/>

Veterans Against Myeloma

<https://www.myeloma.org/veterans-against-myeloma>

Myeloma Hub

<https://www.myeloma-hub.com/>

Cancer.com

<https://www.cancer.com/>

American Society of Hematology (ASH)

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

ASH Clinical News

<https://www.ashclinicalnews.org/multiple-myeloma/>

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COVID-19 INFORMATIONAL LINKS

OncoLink

<https://www.oncolink.org/support/resources/coping-with-covid-19/covid-19-emergency-financial-assistance-for-people-with-cancer>

- **COVID-19 Emergency Financial Assistance for People with Cancer**

60 Minutes Overtime

<https://www.cbsnews.com/news/covid-19-plasma-donation-what-you-need-to-know-60-minutes-2020-05-31/>

- **COVID-19 plasma donation: What you need to know from Dr. Michele Donato, the principal investigator of the therapeutic**

plasma study at Hackensack University Medical Center in New Jersey

International Myeloma Foundation (IMF)

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

Myeloma Patient Safety and the COVID-19

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

- **Patient/Family Seminar – Myeloma Patient Safety and the Coronavirus Replay**
- **COVID-19 Update: Patient Safety More Important Than Ever As States Begin to Reopen**
- **COVID-19 Update: TRUTH, TESTING, AND THE FUTURE**
- **COVID-19 FAQ #7: Is it safe for myeloma patients to take walks?**
- **COVID-19 FAQ #8: Is physical distancing still recommended for myeloma patients?**
- **COVID-19 FAQ #9: Can myeloma patients avoid contracting the COVID-19 infection?**
- **COVID-19 FAQ #10: Should Myeloma patients undergo routine COVID-19 antibody testing?**
- **COVID-19 FAQ #11: Are MGUS and smoldering multiple myeloma (SMM) patients considered to be at higher risk for severe consequences from a COVID-19 infection?**

- **COVID-19 FAQ #12: If a myeloma patient takes Revlimid® (lenalidomide) as maintenance treatment, should this patient continue with that treatment during the pandemic?**
- **COVID-19 FAQ #13: Is it safe for myeloma patients to resume in-person doctors' visits?**
- **Federal Government Response to COVID-19**
- **COVID-19 External Resources:**
 - **World Health Organization**
 - **Centers for Disease Control**
 - **FDA Grants Emergency Use Authorization for COVID-19 Drug**
 - **Cancer Emergency Fund**
 - **FDA: A Message to Patients With Cancer and Health Care Providers About COVID-19**
 - **FDA Issues Guidance for Conducting Clinical Trials**
 - **US Government Response**
 - **Global Dashboard of confirmed cases**
 - **Medicare and Medicaid**
 - **Watch Out for Medicare Fraud (Possible COVID-19 scams)**
 - **VA and Coronavirus**
 - **The American Red Cross: Steps to Help Cope with the Evolving Coronavirus Situation**
 - **Considerations of COVID-19–Specific Myeloma Guidelines in New York City**

- **Multiple Myeloma Medicare Access**
- **PSA Safe Grocery Shopping in COVID-19 Pandemic**
- **How I Am Managing My Patients With Myeloma During the COVID-19 Pandemic**
- **LLS COVID-19 Patient Financial Aid Program**
- **Healthwell Foundation COVID-19 Ancillary Costs Support**
- **Pharma Resources:**
 - **COVID-19 Emergency Food Assistance Program by Team Rubicon and Bristol Myers Squibb**
 - **GSK COVID-19 statement of support Patient Groups**
 - **GSK Compassionate Use (Expanded Access) statement for Patient Groups**
 - **Takeda Oncology Expands Patient Assistance in the U.S. During COVID-19 Crisis**
 - **Takeda Oncology 1 Point portal**
 - **Bristol Myers Squibb COVID-19 patient support**

Global Plasma Leaders Collaborate to Accelerate Development of Potential COVID-19 Hyperimmune Therapy

- **Sanofi and GSK to join forces in unprecedented vaccine collaboration to fight COVID-19**
- **Johnson & Johnson Announces a Lead Vaccine Candidate for COVID-19**
- **Conversations with Dr. Durie - guests Dr. Suzanne Lentzsch and Yelak Biru**

- “...Dr. Durie is joined by Dr. Suzanne Lentzsch of the New York-Presbyterian Hospital, and IMF Board Member and myeloma patient Yelak Biru. Listen as Dr. Suzanne Lentzsch describes her experience working on the front lines of the COVID-19 pandemic in New York City, while Yelak Biru dives into the myeloma patient mindset.”
- The Pandemic, National Crises, and Racial Health Disparities
- Six Months of Coronavirus: Here’s Some of What We’ve Learned
 - <https://www.nytimes.com/article/coronavirus-facts-history.html>

Multiple Myeloma Research Foundation

<https://themmrf.org/>

Coronavirus (COVID-19) & Multiple Myeloma

<https://themmrf.org/2020/03/multiple-myeloma-and-the-coronavirus/>

- How to minimize your risk
- F.A.Q.
 - Multiple Myeloma Transplant and Cellular Therapy:
 - Multiple Myeloma and the Immune System:
 - Medications and COVID-19
- Patient Resources
- Dr. Cho's 'COVID-19 & Multiple Myeloma' Video Series:

- **4.9 - Tips and Resources on Managing Mental Health during COVID-19**
- **4.2 - New Guidance for Myeloma Patients on Maintaining Physical & Emotional Health**
- **3.26 - Dr. Cho answers your Multiple Myeloma and COVID-19 questions**
- **3.18 - MMRF Chief Medical Officer Speaks on COVID-19**
- **MMRF & Levine Cancer Institute COVID-19 Q&A Video Series:**
 - **May 5th Roundtable**
 - **April 28th Roundtable**
 - **April 21st Roundtable**
 - **April 14th Roundtable**
 - **April 7th Roundtable**

Myeloma Crowd

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

- **Finding Financial Resources for Insurance and Prescription Medication Costs with impact of COVID-19**
- **ASCO 2020: An Update on COVID-19 and Cancer Patient Outcomes**
- **Lower COVID Antibody Rates for Cancer Patients**
- **Lessons from COVID-19 to Improve our Health and Life with Myeloma**

Myeloma Crowd Radio

<https://www.blogtalkradio.com/myelomacrowdradio>

- **Myeloma Crowd Radio: Stephen Russell, MD, PhD, Mayo Clinic and Vyriad**
 - **“Antibody testing for COVID-19 is rapidly evolving on a daily basis. Dr. Stephen Russell is developing a new blood-based antibody test to identify neutralizing antibodies that can determine a person's immune defense against SARS-CoV-2. “**
- **Myeloma Crowd Radio: Ola C. Landgren, Memorial Sloan Kettering Cancer Center**
 - **“To date, a select number of myeloma patients have become COVID-19 positive. What have they experienced and how have they fared?”**
 - **COVID-19 Update with Ola Landgren, MD, PhD, MSKCC**
- **Myeloma Crowd Radio: Joshua Richter, MD, Mount Sinai**
 - **“The coronavirus (COVID-19) is causing concern and disruption for normally healthy global citizens, but there are additional issues for multiple myeloma patients who are frequent visitors to hospitals and are often immunocompromised”**

The Myeloma Beacon

<https://myelomabeacon.org/search/covid-19>

- **Karyopharm To Evaluate Low Dose Selinexor As A Potential Treatment For Hospitalized Patients With COVID-19**

- **Kleo Pharmaceuticals And Celularity Enter Into Research Collaboration To Rapidly Develop Allogeneic NK Cell Combination Therapies For COVID-19 And Multiple Myeloma**

CURE

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

- **COVID-19's Impact on How Patients with CLL, Myeloma Have Received Treatment**

Multiple Myeloma Hub

<https://multiplemyelomahub.com/search/?search=covid-19>

- **Safety of trial participants is FDA's top priority in ongoing clinical trials during the COVID-19 outbreak**
- **COVID-HEME forum supports hematologists during COVID-19 pandemic**
- **Management of COVID-19 outbreak on transplant wards**
- **Frequently asked questions | Treating patients with multiple myeloma during the COVID-19 pandemic**

Myeloma Research News

<https://myelomaresearchnews.com/information-about-covid-19-for-myeloma-patients/>

- **Updates**
 - **June 10, 2020**

- June 3, 2020
- May 27, 2020
- May 20, 2020
- May 13, 2020

Patient Power

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

- **Making Sense of New Myeloma Treatments During Coronavirus**
- **Myeloma Treatment Amid the Coronavirus Pandemic**
- **Update on Coronavirus Issues for Myeloma Patients**
- **Myeloma Experts Discuss Coronavirus and Impact on Patient Care**

Leukemia/Lymphoma Society (LLS)

<https://www.lls.org/support/financial-support/covid-19-patient-financial-aid-program>

- **LLS COVID-19 PATIENT FINANCIAL AID Program**

Steroid dexamethasone reduces deaths among patients with severe COVID-19 - trial shows

<https://www.msn.com/en-us/Health/health-news/steroid-dexamethasone-reduces-deaths-among-patients-with-severe-covid-19-trial-shows/ar-BB15yOUf?ocid=se>