

## **CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP NOVEMBER 4, 2020 VIRTUAL MEETING RECAP**

There were 25 members on our Zoom meeting

Guest Speaker: Brian McMahon, SparkCures

Brian is a four-time cancer caregiver and founder of SparkCures. SparkCures helps Multiple Myeloma patients find, understand, and connect with eligible clinical trials around the United States.

Below are a few points from Brian's presentation that I found interesting...

- There are two types of clinical trials
  - Observational
  - Treatment
- There are 3 phases in a clinical trial
  - Phase I – Is the treatment safe and at what dose
  - Phase II – Does the treatment work
  - Phase III - Does the treatment work better than the current standard of care with

- Less side effects
- Easier to administer
- In Phase III, you can have a control arm and the new drug. This is “Randomization”
- If you are enrolled in a trial with randomization and you are in the control arm, there is a “Cross-over” option...if your Multiple Myeloma progresses you can move to the new drug being tested

Brian proceeded to explain how SparkCures works for the Multiple Myeloma patient. This was a very interesting and important speaker topic. We urge all of you to visit the SparkCures website <https://sparkcures.com/> and consider creating a patient profile. After entering a few specifics regarding your Multiple Myeloma and setting some parameters, the website will provide you with available clinical trials across the United States and constantly update them for you, based upon your patient profile. You may not be thinking of joining a trial at this time, but having the knowledge of what trials are available across the United States, is another weapon in your arsenal against this disease.

Miracles for Myeloma

- Update as of November 11, 2020, \$43,369 has been raised! Donations will be accepted until December 12, 2020 at 12:00pm. In lieu of a Holiday gift for that hard to shop for friend or family member, why not consider donation to Miracles in their name!! Be sure to visit the Miracles website at [http://give.myeloma.org/site/TR?fr\\_id=2101&pg=entry](http://give.myeloma.org/site/TR?fr_id=2101&pg=entry)

and click on the “Photos” tab to view photos submitted by participants, as well as the “Remembrance Path” tab to view the virtual Remembrance Path.

Below are Informational Multiple Myeloma Links as well as Informational Multiple Myeloma/COVID Links

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NOVEMBER 4, 2020 MEETING UPDATE  
INFORMATIONAL MYELOMA LINKS**

**International Myeloma Foundation**

<https://www.myeloma.org>

- IMWG's New Risk Stratification Model for Smoldering Myeloma Will Reduce Risk of Disease Progression and End-Organ Damage
- Co-pay Assistance Programs Update (10/7/2020)
- #AskDrDurie

- Should myeloma patients alter their treatment if their protein spike remains low but has not gone away?
- COVID-19 FAQ #23: As the pandemic continues, what does the future hold for myeloma patients?

## **Multiple Myeloma Research Foundation**

<https://themmrf.org/>

## **Myeloma Crowd**

<https://www.myelomacrowd.org>

- New Risk Assessments for Smoldering Myeloma Patients Developed by International Myeloma Working Group
- Using Flow Cytometry Marker CD200 to Predict Multiple Myeloma Outcomes
- Salvage Therapy Examples in Highly Relapsed Multiple Myeloma
- Fall Immunity: Simple Tips for Keeping your Immune System Strong
- Silicone Breast Implants and Multiple Myeloma
- HealthTree University: Autologous Stem Cell Transplant (Part 2 of 3)
- Myeloma Crowd Research Initiative: Diet in MGUS and Smoldering Myeloma to Prevent Progression with Urvi Shah, MD of MSKCC
- Myeloma Crowd Research Initiative: Fitness to Relieve Side Effects and Prevent Smoldering Myeloma Progression with Jens Hillengass, MD, Roswell Park Cancer Institute

- Myeloma Crowd Research Initiative: Stem Cell Transplant Use and Impact in Multiple Myeloma
- Myeloma Crowd Research Initiative: Side Effect Solutions
- Myeloma Crowd Research Initiative: Personalizing Care for Genetic-Specific Multiple Myeloma
- MCRT Webcast: MGUS and Smoldering Myeloma (SMM)

### **Myeloma Crowd Radio**

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

- Full Show: Venetoclax in the Multiple Myeloma Clinic for t(11;14) Patients with Jonathan Kaufman, MD, Emory University

### **Myeloma Beacon**

<https://myelomabeacon.org/>

### **Cure**

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

- The Latest News and Updates in Myeloma
- Adding Darzalex to Standard Treatment for High-Risk Multiple Myeloma May Delay Disease Progression
- Myeloma: The First Remission Is the Deepest
- Program Leads Patients With Cancer on ‘The Right Track’

## **Myeloma Research News**

<https://myelomaresearchnews.com/>

- Radiation Therapy Safe for Myeloma Patients Before CAR T-cell Infusion, Study Finds
- New Nirogacestat Combos to Enter Myeloma Trials, SpringWorks Says
- Potential Cell Therapy for Multiple Myeloma Named Orphan Drug by FDA
- CLR 131 Elicits Promising Response Rates in Triple-refractory Multiple Myeloma Trial
- Darzalex Delays Disease Progression After ASCT, Phase 3 Trial Reports
- 1st Patient Dosed With Investigational T-cell Therapy NEXI-002 in Phase 1/2 Trial
- Glycostem's oNKord Cell-based Therapy Granted FDA Orphan Drug Designation
- Cytovia, Inserm Partnering on NK-based Immunotherapies for Myeloma
- NCI Awards \$1.7M for Bone Therapy Research to Prevent or Delay Cancer Relapse
- Stand Up to Cancer Awards \$100K for Research About Precursor Multiple Myeloma

## **Multiple Myeloma Hub**

<https://multiplemyelomahub.com/>

- How to achieve the best results in patients with high-risk MM
- FDA grants orphan drug status to an investigational NK cell-based therapy for the treatment of multiple myeloma

### **Patient Power**

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

### **ASH Clinical News**

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

### **Healio**

<https://www.healio.com/news/hematology-oncology/myeloma>

- Radiation therapy safe before CAR T-cell infusion for advanced multiple myeloma
- Autologous vs. allogeneic CAR-T: Decisions must be made 'carefully and deliberately'

### **HealthTree University Myeloma**

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

### **SparkCures**

<https://sparkcures.com/>

- Myeloma Support...Personalized.

- “Whether it's clinical trials, treatments or finding a myeloma specialist, we help you understand your myeloma options.”

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**IMPORTANT COVID-19/MM INFORMATIONAL LINKS**

**International Myeloma Foundation**

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

- COVID-19 Update: Science Leads the Way in the Treatment of Myeloma and COVID-19
- The Silver Lining for Myeloma Patients: Drawing on a Lifetime of Experiences
- #ASKDRDURIE COVID-19 FAQs
- COVID-19 External Resources

**Myeloma Crowd**

<https://www.myelomacrowd.org/myeloma-crowd-research-initiative-covid-19-and-multiple-myeloma/>

- Myeloma Crowd Research Initiative: COVID-19 and Multiple Myeloma Study



