

## CENTRAL NEW JERSEY MULTIPLE MYELOMA SUPPORT GROUP

### NOVEMBER 7, 2018 RECAP

This was an open meeting. Below is some information that may be of interest to you...

From [www.myeloma.org](http://www.myeloma.org)

### **#GivingTuesday**

This year the International Myeloma Foundation is participating in #GivingTuesday, a global day dedicated to giving.

You can join the #GivingTuesday movement by giving to the IMF on Tuesday, November 27, 2018.

<https://www.myeloma.org/giving-tuesday>

### **Important Open Enrollment Announcement From the IMF**

“Open enrollment has started, and we want to share some important information with you before you select your plan for the coming year. If you use co-pay assistance cards/coupons from drug manufacturers (not foundations) to help you pay for your medication, you need to be even more diligent when selecting your plan. A number of insurance plans will no longer count co-pay assistance toward a beneficiary’s deductible and maximum out-of-pocket limit. These new policies are referred to as “co-pay accumulator” or “accumulator adjustment programs.” If your

plan adheres to these practices, you may end up unexpectedly paying thousands of dollars more for your medication.

When you choose an insurance plan, be sure to read the fine print and call your insurer to inquire about whether or not co-pay assistance card/coupons will continue to count toward your deductible and maximum out-of-pocket limit. Also, if you hear of plans doing this, please make us aware at [advocacy@myeloma.org](mailto:advocacy@myeloma.org). We are working with a large group of patient advocacy groups to investigate this issue and educate both the public and policy makers about it.”

## **International Myeloma Foundation Patient/Family Seminar – Short Hills, NJ**

**April 7 – April 8, 2019**

Register today!!

[www.myeloma.org/event/imf-patient-family-seminar-short-hills-nj](http://www.myeloma.org/event/imf-patient-family-seminar-short-hills-nj)

## **FDA Weighs in On Immune Therapies**

[www.myeloma.org/blog/dr-duries/fda-weighs-immune-therapies](http://www.myeloma.org/blog/dr-duries/fda-weighs-immune-therapies)

## **ASCENT TRIAL TO TREAT HIGH-RISK SMOLDERING MULTIPLE MYELOMA LAUNCHING ACROSS THE US**

[www.myeloma.org/blog/dr-duries/ascent-trial-treat-high-risk-smoldering-multiple-myeloma-launching-across-us](http://www.myeloma.org/blog/dr-duries/ascent-trial-treat-high-risk-smoldering-multiple-myeloma-launching-across-us)

**IMFTV**

[www.myeloma.org/understanding/imf-tv](http://www.myeloma.org/understanding/imf-tv)

View for some interesting topics...

- New Strategies for Multiple Myeloma Care: Next Steps for the Future
- What is the status of Empliciti® (Elotuzumab), the new immunotherapy?
- How important is the FDA approval of once-weekly dosage of Kyprolis (carfilzomib) for multiple myeloma patients?
- Living Well Teleconference: Clinical Trials in Myeloma
- What are myeloma warriors?

### **Co-Pay Assistance Update**

[www.myeloma.org/article/co-pay-assistance-programs-update](http://www.myeloma.org/article/co-pay-assistance-programs-update)

### **Living Well with Myeloma**

[www.myeloma.org/understanding/imf-tv/living-well-myeloma](http://www.myeloma.org/understanding/imf-tv/living-well-myeloma)

Some interesting topics at this site...

- Living Well Teleconference: Clinical Trials in Myeloma
- Blue Water Navy Vietnam Veterans Act of 2017

### **Myeloma matrix 2.0: smart search**

[www.myeloma.org/matrix](http://www.myeloma.org/matrix)

“Before new drugs or procedures can be approved for use in myeloma, clinical trials must prove that they are safe and more effective than

currently available options. The **Myeloma Matrix** tracks drugs from discovery to development to FDA approval.”

## **Myeloma Minute**

[www.myeloma.org/myeloma-minute](http://www.myeloma.org/myeloma-minute)

Free, weekly email newsletter with up-to-the 'minute' information about myeloma. Here are some interesting topics discussed at this site...

- Volunteering, Giving, and Trailblazing
- High-Risk Smoldering Trial Launching
- Asia Accelerates Myeloma Research
- New Myeloma Imaging Guidelines

## **Myeloma Research News**

<https://myelomaresearchnews.com/>

Visit for some interesting information...

- FDA Clears Way for Trials of FOR46 in Late-stage Multiple Myeloma, Prostate Cancer
- FDA Approves Empliciti Combination for Relapsed or Refractory Multiple Myeloma
- Darzalex Add-on Delays Disease Progression or Death in Newly Diagnosed Multiple Myeloma, Phase 3 Trial Shows
- New Compound Safely Halts Advanced Myeloma Progression in Small Pilot Study

- Trip to Mount Everest's Base Benefits MMRF-funded Multiple Myeloma Research
- Revlimid Delays Disease Progression in Smoldering Myeloma Patients, Preliminary Trial Results Show
- Darzalex Add-on Increases Complete Responses After Stem Cell Transplant, Phase 3 Myeloma Trial Shows
- STRO-001 Receives FDA's Orphan Drug Status for Multiple Myeloma Treatment
- Selinexor Granted Priority Review by FDA for Heavily Treated Multiple Myeloma

## **Myeloma Crowd**

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

Visit for these articles and more...

- FLU SEASON: Preparing and Protecting the Immune System When You Have Multiple Myeloma
- Antibody Drug Conjugates as Immunotherapy in Myeloma
- The Right to Try Act and Means for Myeloma Patients
- Life with Myeloma in Thanksgiving: Ups, Tips of the Season Kathy Cartwright

Also, this information can be found there

How Corticosteroids (Like Dexamethasone) Work to Fight Myeloma

[www.myelomacrowd.org/myeloma-101-dex/](http://www.myelomacrowd.org/myeloma-101-dex/)

You can also listen to these "shows" at [myelomacrowd.org](http://myelomacrowd.org)

Myeloma Crowd Radio

FULL SHOW: Racial disparities in multiple myeloma with Ashraf Badros, md, University of Maryland

FULL SHOW: The largest ever myeloma screening promise study with Irene Ghobrial, md, Dana Farber Cancer Institute and the SU2C Dream Team

FULL SHOW: The new GSK antibody drug conjugate in multiple myeloma with Dr. Maria Chaudhry, OSU James Cancer Center

FULL SHOW: Mid-year myeloma update with Paul Richardson, md of the Dana Farber Cancer Institute

## **OTHER INTERESTING SITES...**

### **Moving Mountains for Multiple Myeloma**

[www.movingmountainsformultiplemyeloma.com](http://www.movingmountainsformultiplemyeloma.com)

### **Myeloma Central**

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

### **SparkCures**

<https://sparkcures.com/>

### **The Myeloma Beacon**

<https://myelomabeacon.org/>

## **Multiple Myeloma Press Releases/The Myeloma Beacon**

<https://myelomabeacon.org/pr/>

## **Veterans Against Myeloma**

[www. veterans.myeloma.org/](http://www.veterans.myeloma.org/)

As we all begin our Holiday shopping, please consider changing Amazon to Amazon Smile to support the IMF!

### **Amazon Smile**

AmazonSmile is a website operated by Amazon with the same products, prices, and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice. Choose the International Myeloma Foundation!

<https://smile.amazon.com/>

On October 4, Frank and I were invited guests at Celgene Pharmaceutical, for their “Employee Appreciation Week”. We met with the employees of the Celgene “Call Center”, where we retold Frank’s myeloma journey, answered questions, and joined them for a catered lunch. The “Call Center” employs those employees myeloma patients speak to when arranging for their Thalidomide, Revlimid, or Pomalyst prescription, where they participate in a health survey before their medication will be released. Many of these employees have been

working in the call center for 10 years or more. They were very happy to meet someone they may have spoken to and their enthusiasm was admirable. For our December meeting we will have Jennifer Chapman, Director, REMS Advisor, as our guest speaker who will discuss the changes being made to the call center, get our group's feedback on the call-in process and discuss a new app that is in the works to be used instead of a call-in survey.

On November 27, Frank and I will be the invited guests of CBI's Bio/Pharma Summit NURSE EDUCATOR PROGRAMS 2018, in Philadelphia. We will be part of a panel discussion on Nurse Educators and Patients, and our experience with Nurse Educators on a personal level and our experience using Nurse Educators as speakers for our Support Group. We are looking forward to this event.

And finally, please take a few moments to take a look at the inspirational video and pictures from Miracles for Myeloma 5K Run/Walk 2018.

### **Miracles for Myeloma 5K Run/Walk 2018 Video**

<https://youtu.be/bky6C2ihoKQ>

### **Miracles for Myeloma 5K Run/Walk 2018 Photos**

<https://qq0u.app.link/e/gLG8PjXBAQ>





