

SUPPORT GROUP MEETING RECAP FOR MAY 3, 2017

Special Guests: Robin Tuohy, Senior Director Support Groups, IMF
Michael Tuohy, Robin's husband and myeloma patient
for 15 years

Robin gave the group an update on the following IMF topics

At the IMF website, <https://www.myeloma.org/>, be sure to visit ...

“Knowledge is Power” section, where you will find the most updated news.

- Co-Pay Assistance Programs Update – this section is checked and updated daily/hourly to be sure funding is still available
- Blogs
- IMFTV – all video and includes the “Ask Dr. Durie” segments

“Living Well with Myeloma Teleconference” section

<https://www.myeloma.org/understanding/imf-tv/living-well-myeloma>

- Nutrition Teleconference coming in May!
- There are many teleconferences to watch and you can print out the slides

“10 Steps to Better Care” section

<https://www.myeloma.org/understanding/10-steps>

The IMF concentrates on four key areas

- Education
 - *60+ publications
 - *seminars that are held in the United States and worldwide
- Support
 - *The IMF support group team members are directly affected by myeloma, either having the disease themselves, or knowing someone who does
 - *150 support groups in the United States
 - *Infoline 800-452-CURE (2873)
 - *The support group leaders team is on the road, attending 244 events this year
 - *8 additional support groups were formed last year and they expect 10-12 new groups this year
 - *Support group leader meetings are held quarterly, where on-line meetings reach 200 leaders
 - *The “Living Well with Myeloma” teleconferences reach 1800 people
 - *There are 137 support group websites
 - *Support group leaders go to ASH (American Society of Hematology) meeting, 1000 leaders worldwide
 - *73 groups use IMF provided technology
- Advocacy
 - *MAM (Myeloma Action Month), which increases myeloma awareness globally
 - * ”3 Points for Patients” - Myeloma awareness initiative between the Boston Celtics and Takeda... \$25,000 raised!!
- Research
 - *Supports and funds Research Grants since 1994
 - *Junior Grant \$50,000
 - *Senior Grant \$80,000

International Myeloma Working Group

- 200 myeloma experts from 34 countries working to cure myeloma
- Developed new diagnostic criteria and treatment guidelines
- Working on advanced MRD methods and recommendations
- Identifying smoldering myeloma guidelines
- Ensure patient focused discussions
- Set expectations with pharmaceutical companies regarding drug costs

Black Swan Research Initiative

- Missing Link? - “Can’t kill what you can’t find”
- MRD- major source of relapse...residual myeloma cells
- MRD testing can find 1myeloma cell out of 1 million cells...no MRD, no myeloma!
- This global approach has developed a precise and sensitive MRD test to track myeloma to the lowest levels as a basis for clinical treatment
- MRD testing is done now with bone marrow, but by the end of the year it could be done with a blood test

ANNOUNCEMENTS

The 5th Annual Miracles for Myeloma 5K Run/Walk will be held on September 23, 2017 in Clark, NJ

<http://give.myeloma.org/miracles2017>

If you register before Mother’s Day using the promo code” Seminar5”, you will receive \$5 off your registration fee! Please be sure to join the “Central Jersey Memorial Team”.

There are still tickets available for the Somerset Patriots Ballgame, to be held on Thursday June 8, 2017 at 7:00 PM. Again, we have won a

raffle and have received 30 free tickets (there is both indoor and outdoor seating). Please respond to this email if you are interested in attending. At this time, we are also taking names of members who would like to bring additional people to the game (original limit was 2). Remember, the tickets are free, but you will be responsible for any food or drink. Please respond to this email if you are interested in doing this, as well.

FYI...The "Donate a Photo" phone app, which has been mentioned previously, is still collecting photos for Myeloma Research. This research is being funded by Johnson and Johnson. To date 15,730 photos have been "donated", funding 629 out of the 1000 blood sample goal. Johnson and Johnson will donate \$1 for every photo "donated" to the IMF. It takes 25 photos to collect 100 blood samples. The app is free, you can "donate" one photo a day, and time is limited!! So, go to your phone's "app store", download this app, and have fun helping the IMF.