

MM Fighters! Support Group Meeting
June 25, 2022
Virtual Meeting

Josh Epworth from the SCCA joined for another two-part presentation, helping the members to better understand what constitutes reliable information on Myeloma, and then fielding the challenges that some of our members have experienced at the SCCA. The first half was educational, the second half enlightening, and both will result in better outcomes for us all.

Thought For The Month

As you grow older, you will discover that you have two hands, one for helping yourself, the other for helping others.

This is what the group exemplifies so very well, as can easily be seen with the responses to Scobie's Stem Cell Transplant question and the attendance and support for the Defeat Myeloma event.

The Defeat Myeloma event was quite warm and sunny, and was a wonderful gathering to celebrate the 10th running of the event. 6 MM Fighters manned our booth, 20 plus members were in attendance and numerous members were kind enough to make donations to this worthy cause, which pushed the events totals on the day of the race over our goal of \$120,000 for the first time ever!

Speaker

Josh provided an interesting guide to the processes that are behind the Myeloma information we read daily. He began with examining why Medical papers are written, and explaining the differences in the study designs behind these papers, including

- Meta-analysis
- Systematic reviews
- Cohort Studies
- Clinical trials, of which the randomized clinical trials are the "gold standard" of oncology clinical research.

Josh next examined the three important questions that must be asked of all studies to ensure that they are reliable, and the many ways that these questions must be examined:

- 1.How valid are the results (or how much does the risk of bias affect the trustworthiness of the results)?
- 2.What are the results?
3. Are these results applicable in clinical medicine?

Josh also looked at what the study results were and how to measure them, thankfully in not too much detail as a great deal of mathematics was involved! He followed this by examining the hazards that can impact such studies, such as

- Not all clinical trials are created equal.
- Not all science journals are created equal.
- Objective data is in the eyes of the beholder.

He expanded upon the above with several examples of each, and examined how to determine the differences between predatory journals versus professional journals by their content as well as the formulation of their studies. Lastly, Josh provided resources that can be depended upon to provide reliable information on Myeloma studies. He stressed that by examining whether any of these reliable journals or organizations were cited in an article is a good way to determine the accuracy of the results.

For more details of Josh's presentation, please look at the copy of the slides that is attached to today's email. There is also a video link of Josh's presentation that provides even more details.

Josh next spent time examining the challenges faced by several group members who are at the SCCA. The majority of these discussions seemed to revolve around Covid procedures, communications and scheduling of appointments at the SCCA. Josh took copious notes and we are providing him with a copy of the video recording so that this can be shared with others at the SCCA.

Since Josh's presentation, I have seen the elevator passenger restrictions posted outside the elevators (nothing inside), and several members have said that they have experienced improvements in the communications with schedulers and nurses, so it seems that Josh is busy! Hopefully this trend continues.

Patient Roundtable

Bud is starting on a new clinical trial REGN 5949, a bi-specific antibody targeting BCMA and CD3. I believe he is the first in the group to be on this study!

Chris' first month on Elotuzumab/Polm/Dex has gone well, but he has experienced some joint pain. Fortunately, Benadryl or Tylenol seems to control this side effect on the day that it occurs.

Bill has completed his Car-T cell treatment and is out of the hospital. A few days of fever were a bit spooky, but he rallied and is doing well.

Una is in the midst of recovery from her second stem cell transplant of the year. Wishing her the best of luck for a smoothly recovery.

After 12 years of Smoldering Myeloma, it looks as if Else will be starting treatment for active Myeloma. It is a difficult development after so many years of being treatment free!

Next MM Fighters! Meetings:

Caregivers Meeting – August 6th, 2022 – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

July 23rd, 2022 – Dr. Sara Lee/Josh Epworth – SCCA – Myeloma 101 – All Questions Myeloma – 10AM – 12:30 PM – Virtual Meeting

August 27th, 2022 – Summer Gathering at the Blau's (West Seattle) – Email to follow

NEW GROUP! Living Alone with Myeloma – please contact Heidi at heidiolsen6308@gmail.com for more information.