MM Fighters! Support Group Meeting
October 23, 2021
Virtual Meeting

This month the MM Fighters were fortunate to have Brian McMahon as our featured speaker. Not only is he the founder of SparkCures and a 4 time cancer caregiver, but he is also a recipient of the 40 under 40 in Cancer Award. Brian's company, SparkCures, helps Multiple Myeloma patients and caregivers navigate the maze of clinical trials, making it much simpler for multiple myeloma patients to find and understand their eligible clinical trial options.

Thought For The Month

Be strong and take charge, for

Life imposes things on you that you can't control, but you still have the choice of how you're going to live through this.

Speaker

Brian became passionate about clinical trials through his interactions with his mother's efforts to locate a clinical trial for her Multiple Myeloma. (He also is involved with 4 different clinical trials dealing with a genetic condition of his own!) He started SparkCures 6 years ago and since then has helped thousands of Multiple Myeloma patients to better understand and identify appropriate clinical trials for their specific conditions and requirements.

Brian began with a timeline of the FDA approved treatments for MM, clearly showing the acceleration of approvals over time, which has also created a very complex treatment environment. He then reviewed the two types of clinical trials (observational and treatment) as well as the three phases of a treatment clinical trial:

Phase 1 – Safety and Dosage
Phase 2 – Treatment Efficacy
Phases 3 – Comparison to Standard of Care

Brian next reviewed access to treatments, starting with Standard of Care, Clinical Trials, Off Label (such as Venetoclax outside of trials) and Compassionate Use. This was followed by his exposing a number of myths surrounding Clinical Trials, finishing up with two key pieces of advice:

- The worst time to search for a clinical trial is when you need one.

- Always ask what impact a treatment or trial will have on future treatment options.

From here Brian transitioned into a description of SparkCures, which offers both doctors and patients free access to clinical trial information. Brian has discovered over time that a good deal of the information publicly available on clinical trials is incorrect, and SparkCures corrects this by confirming information with the individual trials and institutions before making it available on their site.

SparkCures allows you to create list of current and future trials that you are eligible for, in addition to past trials and those that are of no interest (or that you are no longer eligible for). You are updated on a daily basis, helping you stay ahead of the game.

Brian made it clear that SparkCures service is free to patients and doctors, and that SparkCures never sells or shares your information. In addition, they do not let relationships with pharmaceutical firms influence the treatment options they share with patients. While they are a 'for profit' firm, and are paid by pharma firms, they limit their interactions to

- Helping pharmaceutical companies understand why patients ARE NOT eligible.

- Helping pharmaceutical companies understand where patients are UNDERSERVED

In addition to these notes and a copy of his slides, a recording of Brian's presentation is available. This is set up to view online, as it is over 1 hour in length and is too heavy to download. Please let Mari know if you are having any difficulties viewing the presentation – her email is marihattori@gmail.com. The link:

https://drive.google.com/file/d/1685szs5pV8xtW5bCuxMsDnqnmQCwS9KI/view?usp=sharing

Patient Roundtable

Two caregivers of patients who have undergone Car-T cell treatments were able to provide updates, and the news is encouraging! Gary said that his wife is six months out from her treatment and doing well, while Tim's wife Ellen is closing in on 3 years!

Annie provided a news on her Venetoclax treatment, which is not providing the hoped for results. She is also a strong proponent of clinical trials, and she discussed the observational trial she is part of as well as her efforts to join clinical trials.

Pain management was discussed by several members. Every institution handles this differently, with some relying on Palliative Care to guide pain relief, while other locations have a specific Pain Team to address such issues. Your oncologist as well as a pharmacist are also key players in such discussions, with others bringing in certain naturopaths, Physical Therapists and even Acupuncturists. There have been some great reports of non-narcotic pain relief by several members, so there is hope out there!

Vaccines and Covid were also discussed, especially with the holidays fast approaching. The common theme was to do what you are comfortable with, while at the same time taking sensible precautions and minimizing risks. Patients face a much greater risk than vaccinated people, and having patience and taking care of ourselves as well as surrounding ourselves with vaccinated people is key. Home test kits can also help put minds at ease for those traveling from afar.

Getting an AirTamer for patients to wear was suggested as an additional level of protection. This has worked well for many to help avoid colds and the flu when traveling and in crowded locations. While there are no studies regarding AirTamers and Covid, this seems like a simple and very sensible step to take.

Jon provided us with great news regarding his ONJ (osteonecrosis of the jaw). He joined a clinical study at Harborview and just found out that the treatment has yielded very positive results for him. The dead bone was able to be removed and there is healthy tissue and bone underneath. This will be watched carefully, but it seems that his OJN has been healed.

Kathy called in from Bainbridge Island and is still in remission from 2017! Great news!

If all goes as hoped, Una will be joining a clinical trial at Swedish investigating Bites. Fingers crossed for great success!

Ruth mentioned that she employed visualization while getting into remission, seeing her Myeloma cells as salmon and her medications as sea lions, and this seemed to be very effective. Depending on her mood, she also envisioned the Myeloma as M&Ms, which might work better for many of us! Visualization has been effective in many areas, and could be another tool to use against MM.

Next MM Fighters! Meeting:

LAST MEETING OF THE YEAR!

November 13th, 2021 – Dr. Edward Libby – Myeloma 101/All Questions Myeloma – 10AM – 12:30 PM – Virtual Meeting