

MM Fighters! Support Group Meeting
May 30, 2020
First Virtual Meeting

Our first virtual meeting (ever!) this past Saturday went very smoothly, thanks to the generosity of the IMF for allowing us to use this meeting app, to the great cooperation of the 40 members and guests that were on the call as well as due to the hard work of our MM Fighters Board and other members. Special thanks go out to Mari and Ken, our IT gurus, for their help learning about this app and prepping us, as well as to Tom, Una, Tony, Bill, Mimi, Eve, Sherry, Scott, John, Jingdai, Karen, Joe and Marilyn for participating in the test calls and helping to work out the kinks and bugs.

Thoughts For The Month

A couple of thoughts that seems especially applicable to those dealing with the challenges of Multiple Myeloma...

- What comes easy won't last long, and what lasts long won't come easy.

- It's not what we have in life but who we have in our life that matters

Speaker

Dr. Tony Blau, founder **All4Cure**, spoke to our group regarding how his organization connects and benefits patients, clinicians and researchers in the myeloma community, thus helping to spread knowledge and understanding while also accelerating the cure for cancer.

Tony captured the current challenging journey myeloma patients often travel, with multiple decisions being made, often complicated by other health issues, work related problems and the lack of clear indications of effectiveness of treatments. He then helped show how All4Cure helped simplify this process, concentrating treatment information and organizing it in a visual and easily understandable format. Each patient's information is thus able to be easily compared and contrasted to the treatment history of other patients, enabling the patients as well as their oncologists/hematologists to follow the treatment history of similarly challenged patients. This helps to highlight which treatments have been most effective against certain chromosomal mutations, to the benefit of patients and doctors alike.

Tony then walked the group through the process of "on-boarding" with All4Cure, and some of the outstanding results that All4Cure has been able to help achieve. The privacy of each patient's information during this whole process was also emphasized by Tony.

Attached with these notes is a copy of Tony's presentation.

Patient Roundtable

An interesting roundtable followed Tony's presentation. Some of the highlights included:

- Two of our members were among the first to get the new Daratumumab injection, which seems to have been pretty well tolerated so far.
 - o Annie has been getting this injection at the SCCA for a clinical trial over the past several months, and while her treatment has posed some challenges, the injection has cut off hours of infusion time with minimal side effects.
 - o Marilyn was the first patient at Swedish to receive this injection, and was greatly impressed with the preparation and care that the doctors and nurse took to ensure her safety. She has also experienced some side effects, and is continuing to note all reactions to help guide future patients' care.
- A wide ranging discussion on COVID-19 and its impact on myeloma patients and their families covered a number of important issues, including patient protection, doctor and dentist visits as well as its impact on multi-generational families. A real concern was the return to school/travel of children, teenagers and college students, in addition to whether to/how to socially isolate within a house.
 - o It was advised to avoid dentist visits in the short term if you are faced with immune challenges.
 - o One member has been able to isolate more active young adults from himself by floors of their house, and is following a fairly strict regimen for his children's social activities.
 - o Other members do not have the room to isolate in this fashion, or were concerned about the impact of limiting young adults social activities too greatly.
 - o Each family has to decide what fits their lifestyle the best, but the focus should be on how best to protect the health of older adults and those with immune challenges.
 - o Sensible guidelines and commonsense restrictions should be followed, and young adults can be "challenged" with more limitations than from before the virus struck, but of course this needs to fit the family's needs, abilities, lifestyles, etc.
- Alternative care was again a popular topic.
 - o While SCCA and Swedish both offer limited alternative care options, acceptance by oncologists seems to vary greatly. Comparing the care and acceptance at each facility is important if you wish to follow this care path.
 - o Bastyr University is a naturopathic school in Seattle. If you are thinking of exploring options there, be sure to keep your doctors

updated. Not all treatments could mesh well with your current regimen, so you must be careful.

- Having found most common MM treatments to unfortunately be less than effective against his myeloma, one patient is looking for other options to bolster treatments. Dietary changes, alternative treatments and naturopathic options were discussed.

Next MM Fighters! Meeting:

Saturday, June 27th, 2020– 10AM – Noon - Dr. Damian Green, Fred Hutch/UW – CAR-T Cells and Immunotherapy VIRTUAL MEETING

Important Event:

Defeat Myeloma Virtual Run, benefiting myeloma research and clinical trials by Dr. Green and the Fred Hutch. Please donate to this important cause if you are able, as it benefits all myeloma patients. www.defeatmyeloma.com