

# **MM Fighters! Support Group Meeting**

## **June 27, 2020**

### **Virtual Meeting**

The MM Fighters continued with our virtual meetings (thanks again to the IMF for allowing us to “piggyback” on their GoToMeeting app) which went very smoothly despite the last minute discovery of a recent software update that changed the placement of settings for some participants. Thanks again to Ken and Mari, as well as Sherry and Scott, for help with a test session earlier in the week, which gave first time viewers the chance to test their connections.

#### **Thoughts For The Month**

Some thoughts to help all of us gain the right perspective during these trying times...

- I have found that if you love life, life will love you back.
- The way I see it, if you want the rainbow, you gotta put up with the rain.

#### **Speakers**

**Jenny and Paul Alhstrom**, founders of the **Myeloma Crowd**, were joined by **Todd Foster** to introduce the Myeloma Crowd’s Healthtree, an online tool that helps myeloma patients to better understand their disease and the treatment options available to them.

Jenny and Paul took us through the initial development of Healthtree, then reviewed some of the most common and often used parts of their site: tracking your myeloma, a visual understanding of your lab results and how a patient can better understand future treatment options. Other areas of this site that have also proven popular are

- A clinical trial finder – developed and run by their partner SparksCure
- Healthtree University – an educational opportunity for patients and caregivers to learn about multiple myeloma
- Find Your Twin – through the examination of different aspects of your disease, you can locate someone whose disease has run a similar course to yours
- COVID and Myeloma – a recent addition, this examines the interaction of these two challenges

With over 7,000 participants, this has proven to be a popular site. Healthtree tends to be more of a patient centric site, while other similar sites, such as All4Cure, which offering some of the same functions, focuses more on the clinical, or treatment-related aspects of myeloma.

More information can be found at the Myeloma Crowd's website.

### **Patient Roundtable**

Discussions continued this month on new Daratumumab injection, which is being offered at the SCCA and Swedish.

- Annie, who has been receiving this as part of a clinical trial for the past 5 months, feels that the treatment has gone well so far, although the Velcade that she is taking in conjunction with this drug seems to be causing some unwanted side effects.
- Marilyn has stopped taking the Darzalex injection, switching back to the longer Daratumumab infusion as she was getting severe headaches. She believes this is from the additive they have included with the injection.
- Una has started on this drug after 12 years on Revlimid, and her first two injections have gone smoothly.
- The above clearly shows that each of us react to drugs and treatments in different manners. When discussing your disease, possible treatments and the potential side effects with doctors or other patients, do keep this in mind. What they are relating is their experience only...yours can vary!

Naoko mentioned that as she approaches the first anniversary of her stem cell transplant, she tends to get nervous regarding possible results from blood tests.

- Other patients remarked that they went through similar cycles but as time went on this anxiety lessened.
- Others recommended that she look at this more like a game of chess, not worrying what the next move is going to be but what your options are 3 -4 moves in the future will be.
- Understanding your disease and what options you will have if your current treatment becomes ineffective is another long term strategy for minimizing anxiety. By discussing future decision points with your doctors, and what treatments opportunities he suggests, you realize that you are prepared for future challenges, and do not need to focus on the "what if".
- Social worker at your cancer clinic can also suggest other support options.

Another opportunity is to have a group of fellow patients support each other in small group discussions. By forming smaller groups where you can discuss concerns with fewer people around, concerns and anxieties can be minimized.

- All of us receive a list of fellow MM Fighters periodically, so feel free to contact others.

David, a first time visitor to our group, introduced himself and his recent treatments. Being seen at the Polyclinic and SCCA, all seems to be going well. Challenged with a good bit of titanium in his back, he was interested in learning more from Sherry regarding a pain patch that has served her well in dealing with a similar challenge.

The MM Fighters have two contributing authors with the Myeloma Beacon! One of them, Marilyn, suggests that everyone take the opportunity to write about their myeloma, as each of us has a story to tell. If you have an interest in exploring this opportunity, the editor at Myeloma Beacon is Boris: [boris.simkovich@beaconfh.org](mailto:boris.simkovich@beaconfh.org). The person who does the actual editing is Maike: [maike.haele@beaconfh.org](mailto:maike.haele@beaconfh.org). We look forward to more MM Fighters displaying their talents!

The 7<sup>th</sup> Defeat Myeloma Fundraiser was held (virtually) on Sunday, and raised over \$100,000 (going directly into Myeloma research at the Fred Hutch). Thanks to Sarah, who spearheads this effort, as well as the many MM Fighters who have donated funds or raised money for this important event! There are many events that promote myeloma and/or cancer research, so please do your best to contribute time or money when you can. It is our disease, let's own it!

**Next MM Fighters! Meeting:**

**Saturday, July 25<sup>th</sup>, 2020 – 10AM – Noon** – Josh Epworth, PA - SCCA –  
**Understanding Your Lab Results VIRTUAL MEETING**