

**MM Fighters! Support Group Meeting**  
**August 28, 2021**  
**Virtual Meeting**

The dynamic duo of Drs. Sibel and Tony Blau discussed the challenges that COVID presents to the country and immunocompromised patients in particular this month, as well as fielded questions and concerns brought up by the members. It was a sobering view of the current situation, but an affirmation that we are in charge of our welfare, and that straightforward and honest communication and boundaries can protect our health as well as those around us.

**Thought For The Month**

With the many challenges that caregivers and patients face, we are often in a hurry to overcome an obstacle and get on with living our lives, feeling one needs big changes to signal improvement. However, haste can make waste, and it is good to remember that

**Small steps in the right direction can turn out to be the biggest step of your life.**

**Speaker**

Sibel and Tony Blau wasted no time in impressing the members, as their bios illustrate why they could be THE Power Couple for Multiple Myeloma! The organizations and centers that they have founded, chaired or improved have had great impact on the lives of many cancer patients throughout the region and across the US, and their membership in the MM Fighters continue to be a huge benefit to the members. We were fortunate that they were available to speak with us this month.

Sibel started out with a brief history of COVID, highlighting its spread and the appearance of various variant strains. She introduced the various variants that have appeared since the pandemic appeared, and examined why the Delta variant has become so dominant (over 98% of the hospitalizations in WA!).

She then reviewed what a vaccine is, how it works and the various types that have been developed, as well as the standard timeline for the development of a vaccine (easily over 10 years!), comparing it to what occurred with the COVID vaccine, including the fortunate advances/meaningful results that had been made in recent years which enabled the timeline to be drastically shortened without putting the public at risk. Sibel also examined why these vaccines are not as effective against the new variants as it was against the original COVID virus.

The presentation also addressed a misconception that seems to have stopped some from getting a vaccine – the fear of thrombosis, or blood clots. An easy to understand comparative diagram displayed the occurrence of blood clots with the COVID vaccine to Covid itself, smoking and birth control pills, effectively eliminating this as a cause for concern.

While vaccines can not protect 100% against the Covid variants, vaccinated individuals have experienced huge benefits from these shots. Being vaccinated against the Covid virus does lead to much reduced illnesses and reactions, while also minimizing the amount of time an individual carries the virus with them.

Sibel next turned to immuno-compromised patients and the threat that COVID poses for us. The importance of getting a third vaccine shot (all of the same type) can not be overstated. While healthy individuals have a mortality rate of around 5.8% from COVID, cancer patients are at 5 times the risk (28% mortality rate). Unfortunately, blood cancer patients are at even greater risk, with a mortality rate of 37%.

In addition, immuno-compromised patients can harbor the virus for longer, which can lead to the creation of more variant strains of the virus. By receiving the COVID vaccination, patients will harbor the virus for a shorter period of time, thus minimizing the creation of new variants.

Treatment with specific monoclonal antibodies has proved effective for those who have tested positive to COVID. Regeneron (a combination of Casirivimab and imdevimab, also known as REGEN-Cov) is the most commonly mentioned monoclonal anti-body in the news, and has been approved by the FDA.

Binax, a home test kit from Abbott that is available in many places, was also highlighted by Dr. Blau. There are two tests per kit, with the second to be taken three days after the first in case of a positive result. Over 95% accurate for negative tests, approximately 80+% for positive, so another test is strongly encouraged. These tests can be useful for those who are having family visit during the year-end holidays as a quick and accurate way to identify the presence of COVID.

Sibel wrapped up by reviewing the history of COVID in WA, as well as her expectations and some recommendations for all of us to follow. Tony helped drive the point of vigilance home by reviewing the cases of two Myeloma patients' All4Cure dashboards that showed while they had strong responses in their battle with Myeloma, they both succumbed to the COVID virus despite being vaccinated. Make sure those around you are vaccinated and taking the appropriate precautions in order to help form the protective bubble around you!

Sibel's slides are attached to this email.

## **Patient Roundtable**

Lots of discussion centered around the threat that the COVID poses to immune compromised patients, and some felt a bit depressed after the presentation. But as Tony and Sibel pointed out, while the danger is real, taking the right steps and insisting on others following your lead protects us all. By being firm and staying calm, explaining your reasoning and the importance of following your guidelines, you protect yourself and others. It is not always easy, but it is well worth the effort.

There is talk that the next step is a vaccine that will target the Corona virus, thus being able to protect us from all or most of these related viruses that have started to appear in recent years. While there is still a long way to go, it is an interesting new avenue that many are pursuing.

Jon informed us that he has joined a clinical trial to help overcome his jaw necrosis. He is still not assigned an arm in the study (placebo vs. treatment) but our fingers are crossed for him...and for strong results.

Jon also mentioned that he had completed a virtual LiveStrong program offered by the Spokane YMCA. The local chapters have all shut down their LiveStrong programs due to COVID, but this virtual program was open to all cancer patients in the state. Not 100% sure if they will be offering it again, but all those who are interested should contact Jon Jantzen ([jonathan.jantzen@gmail.com](mailto:jonathan.jantzen@gmail.com)) for more details.

Bud, who has had quite the journey with jaw necrosis, shared the good news that he will soon be getting implants so that he can once again tackle solid food...no more eggs and grits!

Dave had great news that he is again walking on the beach up to 7500 steps a day after two great strides forward under the care of City of Hope hospital in CA. Both his back pain and the nerve pain in his leg have been overcome (the latter just recently with a pain patch) and he is overjoyed.

Several members shared their stories of back troubles and how a simple solution such as lumbar support worked wonders for them. Some used a firm support, while others had a bit more expensive fitted device for their car/truck, but definitely something that those experiencing occasional back problems should look into.

Ruth had some great news regarding her treatments, as after over a year of less than spectacular progress from various treatments, her latest drug cocktail seemed to dramatically knock down her cancer counts, impressing even her oncologist! Unfortunately, this treatment also seemed to put her into a dream-like state for several weeks, but the results were by far the best that she has experienced. It is truly wonderful when patients meet the treatment meant for them!

Several members who have undergone stem cell transplants this year are on maintenance or about to start and are doing well. Great to see everyone recover so strongly from that challenge!

**Next MM Fighters! Meeting:**

**Saturday, September 25<sup>th</sup>, 2021** – 10 AM – Noon – **Dr. Sarah Lee, Long Term Survivorship** – **Virtual Meeting**

**October 9<sup>th</sup>, 2021** – **IMF Regional Workshop for Washington State** – details will follow!