

**MM Fighters! Support Group Meeting**  
**November 13, 2021**  
**Virtual Meeting**

For our final meeting of 2021, we had the pleasure to have **Dr. Libby** speak with us on the ever-popular topic of **All Questions Myeloma**. Dr. Libby has been conducting this discussion for a number of years, and each year the members have come away impressed with his attention to detail as well as this willingness to address all topics. This year was no exception, as you will be able to tell from the link to the video of this meeting, which is attached to the email.

Unfortunately, this was also the last time that Dr. Libby will be addressing such questions, as he is retiring at the end of the year. We owe a great debt of gratitude to Dr. Libby for his many years of support for the MM Fighters as well as the MM community in general. As a small token of thanks, the group has presented him with a gift certificate to a favorite restaurant in Olympia (thanks to Jon and Mary Beth for their assistance!).

There were numerous thanks you messages sent to Dr. Libby after his presentation, but unfortunately he had to sign off quickly due to a prior commitment. It would be most appreciated if the members would drop Dr. Libby a note of appreciation for his support to his email address: [elibby@seattlecca.org](mailto:elibby@seattlecca.org).

**Thought For The Month**

As you may be aware, Jenny Ahlstrom, the founder of the Myeloma Crowd, is undergoing Car-T cell therapy due to a relapse in her Myeloma. She included a couple of quotes in her latest blog that are appropriate for all cancer patients.

The first one was from when someone congratulated her husband on Jenny's being diagnosed with Myeloma. When asked why he said this, the friend replied,

**“Now you have the opportunity to see the world differently and to serve in ways you could not have before.”**

The second quote is a guide to help us as we learn to deal with the challenges of Myeloma, as well as the many opportunities available to assist others:

**“Outward service heals the inner soul”**

**Speaker**

The questions came in fast and furious for Dr. Libby, and we kept him answering questions for over 30 minutes past his previously agreed to time limit. I did my best

of keep up with questions and answers, but for a complete recap of these important exchanges, please view the video at the link provided in today's email.

### **MRD and M Spike**

Dr. Libby reviewed an earlier meeting he had where the doctors present discussed the difficulty of reading M spike findings accurately. He felt that with the many advances currently being examined, M Spike readings could be replaced in 3-5 years. MRD is the only way to confirm complete remission, and Adaptive Biotechnologies (based in Seattle) is the only firm that has been FDA approved to measure Myeloma levels via this technology.

### **Importance of Dex**

Dexamethasone, the drug we all love to hate, attacks Myeloma cells on its own (but not terribly effectively). However, when paired with other anti-Myeloma drugs, it has been found to generate a stronger anti-Myeloma response in almost every drug.

### **Various BCMA targeted therapies (Car-T, Bi-specific, Blenrep)**

Dr. Libby felt that if you had a choice, that you should opt for a Car-T cell therapy as your first treatment, then switch to a bi-specific or BlenRep as the next treatment. For patients that are refractory or relapsed, Car-T cell therapy has been found to be very effective, and for a longer period of time than any other treatment. It also has a longer history of proven results. The resulting longer pause in treatments (so far, 9 months up to 2 years on average) will provide more time for the newer therapies to be studied and perhaps improved. And as Car-Ts are mostly clinical trials at this time, the costs are minimal for the patients.

### **Myeloma Patients and Covid**

During the meeting Dr. Libby mentioned that understanding the levels of antibodies produced by the body from Covid vaccines could provide one more piece of information allowing patients to better understand the risks that they face.

### **Older samples of Bone Marrow Biopsies for MRD tests**

As long as these samples contain the correct cells and have been stored correctly, Dr. Libby feels that this is possible.

### **Why Chemotherapy Before Car-T cell therapy**

The chemo is not given to treat the Myeloma, but to help minimize the response of the patient's immune system to these new "invaders", giving the Car-T cells a chance to expand and get established. Otherwise, the immune system would simply attack and most likely wipe out the newly introduced cells.

### **Gene translocation and impact on MM Treatment for high risk patients (such as 4:14 translocation)**

Dr. Libby stated that there has been no change in thinking of how to approach high risk Myeloma.

However, in an email sent to the group on November 20<sup>th</sup> (from the Myeloma Crowd) there was an article regarding some findings from a MMRF backed study at Mt. Sinai. This study found a potential way to reclassify Myeloma related cytogenetics, perhaps laying out a foundation for future treatments targeted at these translocations/deletions/additions. Although still very early, this could lead to some very exciting developments. This can be found at

<https://www.myelomacrowd.org/new-genetic-subdivisions-help-separate-myeloma-risk/>

### **Are there cancerous stem cells in my stored stem cells**

There could be some, but Dr. Libby feels that this does not matter too much. The stem cell transplant is not meant as a curative treatment, but as a way to get a long remission for newly treated patients. The presence of any such cells should not impact the results significantly.

### **Should high risk Smoldering Myeloma be treated**

There is a great deal of researching being done on this, and it is recommended to seek the advice of a Myeloma specialist to discuss options.

### **Older patient (89) and significant weight loss**

This could be, but not necessarily due to your Myeloma. Other cancers, thyroid conditions or the impact of your treatment could all be causes. Again, investigate with a Myeloma specialist.

### **Father and daughter with Myeloma – test kids**

At this time, there is no research indicating heredity in Myeloma. Dr. Libby feels that there is no reason to test children until they are 40-50 years old. It is a simple blood test.

### **Any new findings on treating MM and Amyloidosis**

There is an exciting new drug (please check the video for the name) that helps speed up the removal of amyloids from the body. In addition, Dr. Lee at the SCCA is involved in to clinical trials regarding heart amyloidosis.

### **Patient Roundtable**

A lot of concern was expressed regarding developments at Swedish and/or the SCCA, such as slow response time to questions, lack of support staff, as well as other assorted challenges that patients and caregivers are currently facing. As was mentioned by another member, Evergreen is also experiencing similar problems, so it seems that this is a system wide challenge for the health care industry.

During these trying times, as well as when things are going smoothly, be sure to thank your doctors, nurses and other staff members that assist us during treatment. Unexpected acts of kindness such as this help many people get through their days, and one never knows when such an act can turn someone's day around. And it is too late to thank someone when they are gone!

Several new members introduced themselves as well as their path to diagnosis and recent treatments. Welcome to Bryon and Stephanie.

Katie, whose father has MM, asked for advice on what to expect as her father's stem cell transplant draws closer.

Jon was able to break away to Oregon for some much needed sunshine and scenery, a welcome change from the recent rains that have been hitting the area.

During the next few weeks, surveys for caregivers as well as patients will be sent out to the group. This is a great opportunity to have your voice heard regarding meetings and topics for 2022, so please respond.

**Next MM Fighters! Meeting:**

**January 22<sup>nd</sup>, 2022 - TBD - 10AM - 12:30 PM - Virtual Meeting**