

Summary of ECD Global Alliance Internet Chat

08 July 2017

5 Attendees

- The member who has been having shoulder problems is having a PET this week. This will hopefully show what the situation is after she has had no chemo since April. Her shoulder is now getting better. It will be interesting to see what the scan shows. She will be sending the result on to Dr. Diamond. Dr. Saeed in Lexington will make sure of that! Two weeks ago, she had a brain MRI, which she had the UK send to Dr. Diamond right away.

She was outside the other day for 10 minutes, with a sleeveless shirt and sunscreen. She "got some sun," she will be sure to cover up at the beach!

She hasn't yet had any feedback on her MRI. She thinks that Dr. Diamond may be "a bit miffed" that she is still off chemo. But having had 3+ months off, she thinks that she will qualify if anyone wants her on a new study. She told us that UK now has a molecular tumor board, and Dr. Saeed has communicated with Dr. Diamond. She isn't sure what they might "cook up."

She said that she tells everyone that "I'm fine," but she has low grade fevers in the evening, her legs are hurting, and she is clumsier. She is meeting up with family at the beach in North Carolina for a week, and then she will see her local doctor.

Four of her grandchildren had come over that morning (aged 7, 5, 3, and 1) and she had had to lie down for an hour after they had left!

- A member's wife said that they were thinking about getting him a powered wheelchair, and are looking at the paperwork.
- Our pregnant member is now off of chemo, and was asked how she was, and had she noticed more ECD related symptoms, apart from her instability. She doesn't think that being off medication is good, and she could be doing better. She thinks that she will restart the vemurafenib (V) "the hour after baby is out." If she intends to breastfeed, she may well have to delay restarting V. Hopefully, if she does restart, then she might have more energy and stability to care for the baby! The plan is for starting on four V a day. It was said that she should start with a high dose and have a de-escalating dose schedule to optimize results. The idea is to quickly bring the concentration of V in the blood up, before serious side effects kick in.