

Summary of ECD Global Alliance Internet Chat **June 22, 2019**

8 Attendees

- A US member has now been lined up for a spinal MRI. Dr Diamond told her to take a two week break from Mekinist and she should have started back on it today. But she has a bad cough. Something had been seen at T9, but Dr D had not seen the PET scan. She is not going back again until after an MRI this coming week.

Because of her CNS involvement the US member has two to three brain MRIs a year. This is her first thoracic spine MRI. The lesion seen at T9 has never shown up on a PET. She is known to have a lesion at T7-9 and some other brain lesions.

- The Norwegian member said that her walking was terrible, and she has had another UTI. Her doctors don't know what is going on and they do not speak with any of the ECD specialists, so she feels like she has to do the work. She had an MRI at the end of March but has not had a PET for some years. Everything has been stable.

She is taking one vemurafenib capsule, twice a day. She will be going to Milan for one week. It will be their vacation. She turns 40 on July 9th.

- The US member said that she was 62.

Dr Diamond has started working on a "vacation" idea with medicines. Rather than reducing the dose he is suggesting that the full dose should be taken intermittently.

- The Norwegian member's baby daughter was discussed. She is doing very well. The member said that she would have liked to have had another child if she had been well.

The US member has a daughter in Washington DC who has a son, Oliver (two years old on September 2nd). She is having a girl at the end of September.

Oliver is so busy and wants to figure out everything. He isn't talking yet, but he mimics!

- The Norwegian member said that she had had an MRI in March on her spine and brain. She always has a spine and brain scan together twice a year.