

Summary of ECD Global Alliance Internet Chat **July 14, 2018**

3 Attendees

- Today's chat was started by a member who was away from home attending a family reunion in Wisconsin. She would be returning home tomorrow. While resting she remembered the chat. She has a relative that is a cardiologist and she has been picking his brain. She has been having chest pains, he wonders if it is micro-vascular due to inflammation.
- A member in remission admitted to stopping vemurafenib for a week a couple of weeks back. He is now on one vemurafenib every other day, instead of daily. He began to experience symptoms of facial paralysis, something only typical at high doses, like 6-8 taken daily. He supposes that "bad things" could happen with vemurafenib, even one-a-day if taken long enough. He stated that he may talk to Dr. Diamond about the rationale of taking one vemurafenib every other day now that his face is OK.
His calculation indicated that his dose of one every other day gives about 2+ vemurafenib in the blood. He sees Dr. Garrity and Dr. Habermann at Mayo. Dr. Garrity was the ophthalmologist who was able to tell that he had ECD before checking in at Mayo, by looking at his brain and orbital MRIs.
- A chatter was frustrated with her local oncologist not responding to her contacts. She stated that Dr. Diamond does. Dr. Diamond responds within two hours. She wants to "level with my local doctor about being more proactive." She is also having issues with fingernails falling apart, chest pain, "pulsatile h/a type stuff". She doesn't know if these are side effects or something else. She is taking Mekinist, it may be a side effect of that.
She is due to have a brain MRI and PET scan, but they are not yet scheduled. She is also having issues with her pituitary gland and Dr. Diamond has scheduled her to see a doctor in New York City. She is becoming frustrated with being seen by doctors in two different cities. She would never stop seeing Dr. Diamond, but wants someone she trusts and will work better with Dr. Diamond. She will likely need to travel to New York City more frequently.
- Another member stated that "unless a physician is curious or research-focused, it's hard to get him/her to be proactive."
- Two other members have been through diagnostic workups. Both have been diagnosed with fibromyalgia.