

## **Summary of ECD Global Alliance Internet Chat**

### **26 Nov 2016**

6 Attendees

- During the week a member left a message to say that his in-laws were going to be "using" him to paint their living room, and he would probably miss the Chat.
- A new member came on for the first time. He was diagnosed with ECD last summer. He is from Chicago, 58 years old, and weighs in at 150 pounds! He had acute pericarditis, (an inflammation of the tissue surrounding the heart). He was diagnosed with ECD at Mayo and sees Dr. Go. He is on a dose of three pills in the morning and three in the evening of vemurafenib (V) now, and finds this to be better than 4+4, which gave him a rash, "terrible itch", and headaches.

He had unusual manifestations of the illness. He had two large tumor-like knots on the upper parts of his buttocks. These were the size of baseballs! Biopsy of these lumps confirmed BRAF+ ECD. After two weeks on V at 4+4 per day, they melted away. Dr. Go said he had never seen this before. He has pain behind his shoulder blades, and a PET scan showed these were hot spots. He finds the fatigue very bothersome as he used to be athletic.

He has a weekly appointment with an oncologist and his blood tests are normal now. He has about seven doctors on his "team", all of whom are "intrigued" by the disease. He has a local team of doctors in Chicago who work with Mayo on his case.

He was able to get V treatment authorized by his insurance. He is also a veteran, so the Veteran's Association (VA) has stepped up to assist with the medicine.

He also takes Xarelto (rivaroxaban), having had a blood clot in his lung (a pulmonary embolus). The doctors are unsure whether this was related to the ECD or the result of V treatment. [Summarizer's note; I have never had V, but have also had a pulmonary embolus and take Xarelto. This drug aims to stop the blood forming clots and blocking up arteries. It doesn't make you bleed more if you cut yourself, or make you bruise easily. The old treatment for pulmonary embolus or for deep vein thrombosis was warfarin, which did both of these.]

He also has palmar-plantar erythrodysesthesia, but it is starting to dissipate. It was very painful.

- The ease of getting V treatment approved was discussed. This depends a lot on your insurance coverage. A Canadian member on V may not have coverage next year. They are looking into preparing for alternative funding. In Canada, V costs between 4,000\$ to 6,000\$ Canadian/CAD per month. Some insurance companies are very picky about coverage, and sometimes picky about PET scans, too.
- The overall access situation is getting better as more and more technical papers with positive results have been published. Also, ECD is now considered a cancer (the WHO has recently classified it as a "histiocytic neoplasm"). Both of these are making it easier for patients to get experimental treatments approved.
- Genentech will have a patent on V; but competitor drugs, like dabrafenib (D), are being introduced. Dabrafenib is looking pretty good for patients as well. (The member who is painting living rooms has been on D!)
- After the Chat had finished, a member came on and apologized for missing the Chat. She said that she has been doing pretty well, with her main problem being joint pains.