

Summary of ECD Global Alliance Internet Chat **June 2, 2018**

5 Attendees

- The first chatter was new, a 66-year-old from San Juan, Puerto Rico. She was diagnosed with Diabetes Insipidus in 2008 which was controlled with DDAVP. She developed problems with balance, weakness and dysarthria in 2015, and was diagnosed with ECD last year, after having a cerebellar biopsy done at Mayo Clinic-Rochester, MN. She is being treated by Dr. Diamond at Memorial Sloan Kettering Cancer Center (MSK). She is Braf+, and currently takes dabrafenib(D) 100mg twice a day and desmopressin. Her most recent results are from April 2018. Her PET scan and MRI showed positive results, as did her lab tests. She still has problems with coordination, balance, and weakness; but the cerebellar lesion is not present on her Brain MRI, and her dysarthria has greatly improved. She has not had any side effects from the D, other than thinning of her hair. She is pain free. She has had occasional drooling, night sweats, cough, loss of appetite and weight, but nothing dramatic. She stopped driving almost two years ago, and finds that working with numbers on a computer is hard. She is not exercising at all. "Just thinking about it makes me tired."
- Another new chatter came on. Her mother has just been given a diagnosis of ECD, or Rosai Dorfman Disease. She lives in Turkey and her mother lives in Turkmenistan. The disease has affected her lungs, knees, and skin. She had a lot of pain in her back and knees, and finds it hard to breathe. She has had a skin biopsy done and a MRI scan. The doctors are not sure which disease it is and they have not said what can be done to help. She has also not been given any medications. The chatter asked for information about treatments and side-effects.
- A member from the US came on, and said that she had just heard of another patient in Kentucky who was diagnosed a few months ago with ECD. She used to be only one of two in Kentucky, "not any more!" She had had a colonoscopy that week, showing two polyps, but nothing else.

Her Doc said that there were four ECD patients in Kentucky now. Two of them are BRAF negative, so he is using Pegalyated Interferon on them and also consulting with Dr. Diamond. She told the doctor that he almost has enough patients to be considered a center for ECD! "He didn't seem too excited!"
- A member said that he is due to go to Houston in July.
- Another said that she had grown up in Memorial Drive in Houston, and another chatter said that "That is a pretty nice neighborhood." Her father worked for Exxon, and built a house out there, when the road was just a shell road off of Memorial in 1957. They used to ride the horse down Memorial Drive!
- The growth of the bluebonnets this year was discussed. They have been very pretty and large this year. One member had scattered some seeds in her garden, "but generally it's too cold here for them."
- A member came on who had ECD and lymphoma. She has been taking Kineret for several years (this has also helped her rheumatoid arthritis). Her last PET scan showed good results on ECD and the lymphoma.
- There was one chatter using vemurafenib (V) 2+2 daily.

- There was mention of the study in Bethesda, and of people going back for review.