

Summary of ECD Global Alliance Internet Chat

10 Sept 2016

4 Attendees

- A short and small Chat this week. Before it started a note was left by someone (me) that I would be tucked up in bed at chat time. I also said that Charles (Oz) had dropped by for coffee on his way around the world. We will be seeing him again this week in Paris.
- Two US members chatted about their illnesses. One is fairly new to the Chat. She is from Minnesota and was diagnosed just 7 months ago. She had seen at least 5 different types of doctors before she was diagnosed. Her symptoms were very painful swollen eyes. The eye doctor knew right away that it was ECD before he even did the biopsy to confirm things! She goes to Mayo, takes interferon, and is BRAF negative. Her eyes are not much better. The PET scan said that the disease is stabilizing.
- The other member said that she had been diagnosed 18 months ago and she lives in Lexington, Kentucky. She goes to Memorial Sloan Kettering in NYC for treatment, and also sees a local oncologist in Lexington. Her main areas of disease are her bones, cerebellum, and skin. She had first gone to Mayo, but did not see any doctor who had even heard of ECD, and so they weren't looking for it. She ended up being diagnosed at Duke.
- Then Wedding Anniversaries were discussed. One member had her anniversary coming up on the next day (34 years!). She and her husband are going out to eat at a seafood restaurant.
- The other member also has her anniversary on the very same day (19 years this time!). They are going to be up early to go and try their luck at goose-hunting.
- Another member came on and told us that her anniversary is not until Jan 18th (25 years and counting).