

Summary of ECD Global Alliance Internet Chat

15 Oct 2016

5 Attendees

- A member came on who was hiking in the North Carolina mountains. Her Internet coverage was not good. She said that her joint pains didn't stop her from doing "a little hiking in perfect weather"! She is now seeing "a doctor who only does acupuncture" and is hoping that this will help.
She has just finished some balance physical therapy and will keep doing the exercises. But with her having cerebellum issues, the dizziness may not get better, although she can work on having better balance.
- A member came who has just learned that he is BRAF positive. His treatment is planned to be Kineret for 6 months, and he is going to try to see his rheumatologist in Strasbourg for half of his "on-site" consultations.
- A member from Nepal came just to say hallo.
- The wife of an Canadian member came on to say that he was doing OK on his vemurafenib. They are waiting for the results of a lot of MRI and CAT scans to come back at the end of the month.