

Summary of ECD Global Alliance Internet Chat **March 10, 2018**

7 Attendees

- Another very quiet week on the Chat. The clocks begin to change next week and that will need some thinking about.
- A US member came on. He is 56, has been married for nearly 20 years, and been an ECD patient for 11 years. He said that he was "pretty good." He doesn't know his Braf status, but should find out soon.
- A new chatter came on. He is 33 years old and from Southern Italy. He was diagnosed with diabetes insipidus in 2007. He was treated with interferon for two years, but found this medicine to be "too heavy." During this time his balance worsened. He has been to Paris twice. Since he is Braf+, he was started on vemurafenib (V). He took V for three years (3 in the morning and 3 at night). He had to stop in March 2017 because of liver toxicity. His symptoms worsened: weakness, loss of coordination, and dysarthria. He restarted V on 1+1 with no result. Then, in October, he increased to 2+2 and the symptoms improved. But, in January, he felt that things were going wrong again. He went up to 3+3 at the end of January 2018 and for now "that is good."
- A chatter asked again about the length of time that you should take interferon. She has been on it since June 2015. Her doctor wants her to stay on it, but she has more pain in her bones and joints. Unfortunately, nobody left any replies for her.
- Our French member came on. He has had ECD for three years, and is Braf+.