

Summary of ECD Global Alliance Internet Chat **April 14, 2018**

5 Attendees

- Weather was discussed with one member expecting 10-12 inches of snow, another has had a temp in the 70s, but this is going down to the 40s.
- A member has been taking dabrafenib (D), with a dose of one in the morning and one in the evening (1+1), since March and he doesn't feel any different than before.
- A member had been on D + trametinib (T), but is now only on T.
- Another is fine on one vemurafenib (V) daily, and another is on 1+1 vemurafenib (V), although her balance is still not that good. She can't walk more than a couple of steps without support from something or someone. The member on one V was interested in trying D, but since he is doing ok with V, the copay is just \$5 now, there is no reason to do anything else.
- A member said that he had been taking V for four years now. His experience is, regarding maintenance, you should go with a low dose (like 1+1 or one daily) with daily exercise. "Exercise is key in fighting fatigue." He has been taking one V a day for 2.5 years. He takes it before bedtime and has had no relapses.
- Another said that he was diagnosed in 2015 in "God-awful shape." Within a month on V he was looking and feeling much better. Vemurafenib had bad effects on his liver so he switched to D in 2016, and is still taking this drug. He wakes up at 4:30 in the morning, so he likes to be in bed by 9 pm. V worked very well for him, "but that's because I was on 4+4 for six months." He likes D because he can go out in the sun and not worry.
- A chatter who goes to Memorial Sloan Kettering (MSK) in New York City to see Dr. Diamond also works full-time taking care of 24 Kindergarteners!
- One chatter had been diagnosed at Mayo in 2014, but decided to go to MSK for the V trial until late 2015. He can remember the time when NYC was, literally, his home for over 2.5 years.
- Since V has such a long half-life (57 hours) one a day is equivalent to about an average of 3.5 V's in your blood if you are in remission.