

## **Summary of ECD Global Alliance Internet Chat** **June 9, 2018**

### **3 Attendees**

- Only two chatters joined this week. Finally, there was a late arrival who was temporarily in a different time zone.
- One chatter has been on a dose of one vemurafenib (V) a day for two years, and started on V in May 2014. The other is on three V a day and has been on V since February 2015.
- One was in the trial at Memorial Sloan Kettering and now visits doctors just twice a year at Mayo. The other got V funded through the Veterans Affairs. He is said to be stable, but hasn't got much energy and getting short of breath. He is now 70 years old.
- The other has been in remission for 2+ years. He doesn't have any significant problems, just some rashes from the V and sun sensitivity (even on one daily). He tries to exercise daily and finds this very helpful. He is 55 years old.
- The first is still sun sensitive and burns easily. It was suggested that he might cut back to two V instead of three. Vemurafenib has a 52-hour half-life; taking two daily, you are retaining 7-8 in your body at once.