

## **Summary Of ECD Global Alliance Internet Chat** **17 Sept 2016**

### 4 Attendees

- Short and sweet this week. Many of the Chatters were in Paris at the conference and would have just finished their dinner.
- A member said that he may have made an "interesting discovery" this week. It is something called "Matcha", derived from green tea, and "has a boat load of antioxidants".
- The member who changed from vemurafenib (V) to dabrafenib (D), because his liver enzymes started to rise, said that he is still in remission. He is taking 150mg in am and pm, and thinks that he will be dropping the dose next month. He thinks that Dr. Diamond wants him to have the full dose for 6 months. He had thought that his eyes were perfect again while on the V, but after being on D he sees a huge difference. D hasn't caused him any skin problems.  
He is not on a clinical trial, but he said that "My wife's insurance is goood". He is on her policy and this is with Empire NYship.  
There is now no abnormality on the MRI of his brain, but a "little stuff" in his face and neck. Dr. D had told him back in July that he has a patient who came off completely, and takes 1 methotrexate pill every week or so.  
[Summarizer's comment; I have been taking 40mg methotrexate once a week for some years. It is my only treatment and I've been in remission for the last year. BRAF and V had not been "invented" when I was diagnosed!]
- It was said that V may get FDA approval by the end of the year. D seems to be even better, so hopefully D will also get approved, since V and D are functionally equivalent.
- One member on the Chat told us that he has been on V for about 2 years, and there are no plans to change.
- A member came on who had been to the Paris conference on the day before. He said that he had learnt many things about the disease, particularly what symptoms he can expect to get!