

## **Summary of ECD Global Alliance Internet Chat**

### **06 AUG 2016**

4 Attendees

- A French member told us that he will be hospitalized in Paris, under the care of Professor Haroche at the end of this month. He was there 2 weeks ago for 3 days, in the endocrinology department because of diabetes insipidus. He is expecting to start pegasys (interferon with extended half-life so only weekly injections). He will have his first treatment in the hospital to see any reaction, and he expects to be in for 3 days. He doesn't know his BRAF status.  
After hospitalization in Paris he will go on a spa treatment for 3 weeks, and he will be at the convention in September. He may be a translator during the conference. He lives near Strasbourg on the border with Germany. He said that he could "just interrupt" the spa for a day and, using the high-speed train, go to Paris and back in the space of two days.
- The wife of a member who has been doing well on vemurafenib (V) said that he was better regarding his skin infection. But they have increased the dosage of his pills, so he is a bit more tired than usual. He had a fall the other day from his chair, and his knees are still recovering. As regards to the antidepressant medication, he was able to have 2 hours discussion with their youngest about comics the other day and laugh at a joke made. He is still taking a dose of 2 V in the morning and 2 in the evening. It is the meds that he is taking for his other health issues, including depression, that have been increased. They will not be going to the conference.
- A member from Norway said that she will attend the Paris event [Summarizer's comment; my wife and I are going to be there too]. This Norwegian member has given some presentations to other staff at her workplace, and these were said to have gone well. We now have an "experienced" public speaker in our ranks. She tries to exercise every day "a day with no exercise is not a good day". She is still on 1+1 V a day. Her oncologist said that she would probably have to take that for the rest of her life! She was asked whether she had considered changing to dabrafenib, as then it would just be one tablet a day!