

## **Summary of ECD Global Alliance Chat** **November 11, 2017**

6 Attendees

- One member started the chat by mentioning that the FDA approval of vemurafenib was “truly a day to celebrate!”
- One patient said they were taking dabrafenib, with Mekinist, to help with the side effects.
- A patient who had a long break from vemurafenib has now been back on the drug for five and a half weeks. They are on a dose of one in the morning and one in the evening. Already there have been some positive changes on the MRI. Exercise and physiotherapy is now very important.
- Another patient said that when they went back on dabrafenib after two and a half months off, there were some improvements noted on the PET scan.
- One patient suffers from choking on a regular basis and is having a fluoroscopy swallow test soon.
- A patient mentioned about their lack of energy; they could easily go to sleep at 4:30 pm, but try to stay awake until 9:30 pm each night.
- There was a discussion about the social side of the ECD conference. Members enjoyed meeting other patients and their relatives.
- There was a discussion about the vemurafenib trial; details are on the [ECD website](#).