

## **Summary of ECD Global Alliance Internet Chat January 20, 2018**

5 Attendees

- One member described how they had been on the full dose of dabrafenib for one year, then a dose of two in the morning and two in the evening since April.
- A patient told the group that they had been on one vemurafenib a day for a while now. They are doing well and can tolerate some sun. The issues with sun sensitivity and vemurafenib were discussed.
- A patient said that liver enzymes had increased whilst on vemurafenib; this is the reason that they came off the drug. Another patient was also having liver enzymes tested currently.
- A patient was having a PET scan and brain MRI scan in a couple of weeks. These might indicate whether the dabrafenib and mekinist were working together. The patient was doing well with exercise, but still had problems with balance and pain in the left hip.