

## **Summary of ECD Global Alliance Internet Chat** **15 July 2017**

7 Attendees

- Our member, who has stopped vemurafenib (V) while she is pregnant, said that her walking was much worse.
- Our French member is busy harvesting his vegetables. There is a village wine festival coming up. He goes to see Dr. Haroche in October. He is also going on a three week "Cure" (presumably at a Spa somewhere). He has been taking Kineret for one year now. His eyes feel tired and he has had the return of very strong pains after 10 years.
- A member now in remission said that he had been diagnosed in May 2014. He went on a clinical trial of V at Memorial Sloan Kettering. He requested the doctor to test for the BRAF mutation and, luckily, there was enough tissue for a test. He thinks that V and dabrafenib (D) are better drugs for ECD than Kineret.
- The French member still does not know his BRAF status. He did have a bone biopsy, but there was not enough material to test for BRAF. Dr. Haroche has hesitated to give him V because of the risk of depression.
- The wife of the member whose QT interval had lengthened came on. When he reduced V, the interval went normal, but on increasing the V again, it has lengthened. So, back to the reduced dose.