

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

### **3 Sept 2016**

4 Attendees

- The end of the summer holidays and the start of a new school term were mentioned. We were told that in Norway school had started 2 weeks before!
- The wife of a member told us that he had seen the doctor that week. His QT interval (a measure of electrical activity in the heart muscle) has decreased, and he is now back on a dose of 2 in the morning and 2 in the evening of vemurafenib (V). An ultrasound has been requested (but she didn't say what area it was to be of).

He is on antibiotics because of a wound problem. He also sees a doctor regarding this, and a wound nurse. The wound is on his lower back, next to the spine.

When his V was reduced to 1+1 for one week, due to the raised QT interval, he felt "different". Now back on 2+ 2 he is better and more talkative. His voice, swallowing, the ability to use the right hand, and his balance were all affected by the decrease in dosage. He is still in the therapeutic phase of V treatment. He is also having to deal with other health issues (depression, the heart problem, etc), so there is more than just the V that could be involved.
- Members said that they were looking forward to the upcoming conference. The member who lives in Norway, goes to Paris and sees Professor Haroche. She is looking forward to talking with him. She is in remission now and only goes for blood work about once a year. It is over a year since her last scan.
- A member who has recently dropped her V dose to 1+1 said that she doesn't "really notice a difference". She is still ataxic, dizzy, and still has joint pain, as well as tiredness. But, her scans were stable 2 weeks ago.

She exercises for about 45 minutes, 6 days a week. She is also doing exercises to help with her balance. She thinks that it could all be due to the ECD, the chemo, "or me!". There is no talk of remission, she is just no worse.

She asked the member who reduced her dose a while ago whether any joint pain eventually subsided when she had dropped her V dose to 1+1. The answer was no. Another member who is now on a reduced dose of V, said that he never had joint pain, except when he was on 8 pills a day.
- It was said that during the therapeutic phase of V treatment, monitoring should be monthly. Once you are stable there should be blood work every 3-4 months, although most doctors still want it done monthly.
- The difference between "therapeutic" and "stable" ECD was said to be when your scans are the same on 3-4 consecutive times, and you're not getting much more out of the drugs. If symptoms aren't going away, or getting worse, then you are still in the therapeutic phase. You may need to switch drugs.

It was said that Dabrafenib (D) was very good. One member said that he would like to go back to Memorial Sloan Kettering in New York and get put on it, but he "Just can't afford it at this time." His insurance premium is now very high and coverage is not good. With a high premium, high out-of-pocket max, and outstanding bills, his options are very limited.