

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

**3 June 2017**

4 Attendees

- The member who has recently had shoulder surgery said that it hurts more now than before surgery. She can't drive, so her husband took her to the grocery that morning. She thinks that it is painful and taking time to settle down because the biceps tendon was taken off the shoulder and reinserted in the humerus bone. She is taking 5 mg of hydrocodeine at night to sleep. She took Tylenol earlier that day, but it didn't help. She uses ice every four hours for about 30 minutes.

She is having a brain MRI late June and has had no chemo since April. Since the shoulder problem doesn't seem to be due to the ECD, or its treatment, she is going to a rheumatologist next month to check about autoimmune disorders, "Just one more doctor."

She thinks that if the ECD restarts, it will probably be in her head like it was before, and if the ECD is worse she expects that Dr. Diamond, and her new oncologist, will go for a MEK inhibitor. "I think I've worn out the Vem and Dab."

- The wife of a member said that their youngest child had been to see him (he lives in sheltered accommodation). He has recently had his dose of vemurafenib (V) halved. He is clumsier, but his thought processes are clearer. They are awaiting further news about the QT interval in his heart. This had increased, and that was why the V was reduced.
- A member, who is now in remission, said that when he was on 6-8 V's a day, he had to wake up in the middle of the night to ice his hands and feet so as to cool them down. He also carried an ice chest everywhere he went! At one V a day, he doesn't have any problems and almost no side effects. He had night sweats a lot, when the ECD was bad, with weird dreams and hallucinations. At that time there were tumors all over his brain.
- A member who has been waiting for a long time to have his BRAF status worked out has had a puncture of the sternum (breastbone), but the blood was coagulated. He doesn't yet know how they will want to proceed.
- One member had had a tissue sample taken from the "hairy bit" around his kidneys. Another had a bone marrow aspiration after two skin biopsies failed to give information. It was said that it is very easy now to test for BRAF status using urine or blood testing.
- Migraines were discussed. One member did have migraines throughout his time at college. "It was so bad I spent more time in bed than studying." Another had had migraine since he was a child, although he doesn't complain about them much now.
- One member had had them from the ages of 6 to 56 years, with feelings of vertigo that grew stronger over recent years. He no longer has so many migraines, but he has pains elsewhere in the body!