

## **Summary of ECD Global Alliance Internet Chat** **October 7, 2017**

7 Attendees

- One member said that their feet were suffering, due to Dabrafenib (D), and they could hardly walk due to nerve issues on the balls of their feet. They were also suffering from hip and spine pain, which they thought was disease related. This member has started to attend an integrative health unit. During the sessions they stand on a total body vibrator for 12 minutes, use a PEMF pad to see if that will help the pain and take naps in the wave therapy room. This member is scheduled for three MRIs (brain, spine, and pelvic) and a PET scan shortly.
- A patient mentioned that they had had little respite after three weeks of spa treatment. They had had a lot of pain during the first two weeks. There was less pain in the hands now, but their legs were always painful. The patient has physiotherapy sessions twice a week. This patient is on Kineret.
- One patient had come off D for three and a half months. They had no regrets; they had enjoyed a wonderful summer with their children. During this time they felt that their balance had become a bit worse and their legs had started to hurt. Doctors had been in discussion as to whether another MEK inhibitor could be used if the patient had to change treatment.
- One patient is undergoing extensive tests to see whether they are BRAF positive.
- A member mentioned that they thought that insurance companies do not usually reimburse for mutation tests.
- One patient has recently had a baby, who is doing very well. Congratulations and good wishes were offered by all! The patient started back on vemurafenib (V) one day after the birth with a dose of two pills a day. They had an MRI one day after the birth and further MRI scans are scheduled for ten days time and one months time. After five months, without V, the disease has returned and there is new lesion in the spine.