

## Summary of ECD Global Alliance Internet Chat October 14, 2017

6 Attendees

- One member said that their feet were very painful, and thought this was probably due to dabrafenib. There were growths, from the chemo, on the balls of the feet. They were also suffering from pain in the spine, at the lower end, and in their hips. MRI and PET scans are scheduled in the next six days.
- There were discussions regarding attending the ECD conference in New York in late October.
- One member, whose spouse was diagnosed last year, is on vemurafenib. Another member's spouse was also diagnosed last year.
- One patient sees a doctor locally, and also Dr. Diamond at Memorial Sloan-Kettering. Another patient sees Dr. Lloyd Damon in San Francisco; this doctor has a few ECD patients now.
- One member said that their spouse was taking Gleevec, but it was not working. The patient had been on interferon, which worked for a while, but was then ineffective. The patient suffers from fluid in the stomach, that has to be drained at least once a day. The patient is BRAF negative.
- One member expressed the view that doctors in a 'for profit, and not a research setting' were not generally interested in patients with rare diseases.
- One patient said that they had been on interferon since 2007 and had been stable since then.
- It was mentioned that there is a Facebook site for ECD caregivers, which has regular chats, usually on a Saturday. The chats are advertised several days in advance.
- One patient takes dabrafenib. They used to take vemurafenib, but experienced too many side effects. This patient is BRAF positive.
- A member pointed out that vemurafenib can cause sunburn.
- One patient has started again on vemurafenib, after a five-month break. They are on a dose of one in the morning and one in the evening. This patient is BRAF positive.
- One member said that once you have an 'ECD doctor', that it helps in dealing with other doctors if needed. They said that one of the key things that helped with their spouse was promoting communication between the doctors involved.
- One patient has taken Kineret (anakinra) for five years, with only a short break due to being diagnosed with another cancer. This patient is BRAF negative and sees Dr. Janku at MDAnderson.