

Summary of ECD Global Alliance Chat

22 April 2017

6 Attendees

- A member told us that he had just been food shopping. "Now that the food is put away, I am going to the hospital to visit my dad." His dad has been in the hospital for a while now, but is "making tremendous progress". It looks like his dad will be going to a rehabilitation center, to help him regain his strength and coordination of his muscles.

The member himself has changed from vemurafenib (V) to dabrafenib (D) and the D is "being extremely kind" to him. He is entering the last month on the full dose, making an entire year of treatment, and the dose should be decreasing soon.

- A member said that his wife had taken him "for gardening", but he is tired after just one hour. When he works in the garden he quickly gets out of breath. He also needs to care for his chickens, and he enjoys doing that. He has three that are laying and has had to install them in separate boxes. He lives in the country. The chickens need him to get up in the morning and he has to force himself, but he thinks that it does him good.
- Another member, who has also changed from V to D, has been off treatment for almost two weeks, and is due to have no chemo for another two weeks. Her joints have been a real problem, although they are "not better off the chemo". Whatever the outcome, she hopes that she won't have to "completely cover up in the sun". A member is taking Vitamin D3 daily to make up the deficiency caused by lack of sun exposure.
- A member in remission after V is not feeling so good and her MRI shows "A little more activity". She hasn't changed her treatment yet, but the doctor suggested going back to 2 V a day. She was told that she could monitor her BRAF status, either using Trovogene (urine-based) or a number of other plasma-based solutions. This is inexpensive and it's covered by insurance in the US. You get a kit from them, and send the urine sample to their lab.
- A member thought that once every other month or so would be good to monitor the BRAF status. She hasn't checked her BRAF status since 2013. She was told that as long as she was still on V she would be BRAF-.
- It was suggested that the member who is completely off V and D should do a test for BRAF every so often. She should get a positive reading on the urine test, 2-3 months before a visible flare up! Doing BRAF testing outside a clinical trial is not free.