

Summary of ECD Global Alliance Internet Chat

28 Jan 2017

7 Attendees

- One of the members on Darafenib (D) told us that he was doing fine, but had broken out in hives for about a week, so he stopped the D for four days. Dr. Diamond does not think it is related to the drug. The member is pretty sure too, as he is back on three pills in the morning and three in the evening of D "and the hives aren't happening". The only dietary change that he can think of has been fresh jalapenos.
He had had a scan the previous week and there are now "no hot spots". He has a PET and a brain MRI each visit. The lesions seen on MRI were showing great improvement on the scan back in July. It was mentioned then that there was a little by the brainstem. The doctor said that there is now nothing left.
Dr. Diamond could have reduced his dose now, but the member would have to get a scan every four months to make sure that the lower dose was still effective. He does not want to have scans that frequently. [Summarizer: I think that he once told us that his wife makes him sleep in the other room! 😊] The "other plan" would be to keep him on the full dose for a year (which is May), then drop back and get an MRI every 2-3 months and a PET every 6-8 months.
With regards to side-effects D has been a lot better than vemurafenib (V) for him, and it seems to have dealt with any lesions that remained after coming off V.
- Another member has also swapped from V to D recently. It was said that it looks like D could be great for both therapeutic and maintenance for Braf+ patients.
- The V trial is still going. Some patients are going there, but only once every three months. The FDA still has not approved V, and although the insurance companies are paying for it, they could stop doing so at any time.
- A member who is on the V trial said "So far so good". He has been on the trial for about two years. His V dose was reduced some time ago, he is now on 2+2 and is "mostly stable". The tumor on his heart is SLOWLY getting smaller.
- Then members spoke about the recent finding of a new mutation (KRAS). There are drugs that are used against this mutation, and it was said that there are tests effective in detecting it.
- A member has started going to a cognitive behavior course, which he enjoys but finds rather tiring. The course involves a lot of exercise, physically and mentally. Another person on the course said that she was now able to put her pain at the back, rather than at the front of her life. His wife thinks that he has been "more open" and was able to have more regular conversation, "before he shut down again". There is a meditation disc that comes with the course.