

Summary of ECD Global Alliance Internet Chat

29 April 2017

8 Attendees

- A member said that he was watching Discovery, an unusually different sort of program, that night and this would affect his presence on the Chat. He is still using Intron three times a week. His imaging has been set up by his oncologist after a recent visit.
- A member who had changed from vemurafenib (V) to dabrafenib (D) said that he was doing well and approaching his one year anniversary on the D. He takes 150mg am and pm. He has no plans to switch to something else for maintenance. "I love D" he said. He accepts that he might be a "guinea pig" of sorts, because he hasn't heard of anyone else being on full dose D when their ECD is "super inactive". He only needs an affective maintenance treatment now. He would like to reduce the dose of D if he doesn't need to be on as much as he is currently.
- A member, who is in remission post V treatment, is now just taking one V a day now, before bedtime. He has been on V since May 2014, starting with 4+4 a day, now down to just one a day.
- A US member said that he was surprised that still no drugs have been officially approved by the FDA for ECD, despite all the successful results and publications. Some patients have been on the V trial since 2013, and are still "doing great"! Getting at least one or two drugs approved would gain awareness and visibility for future trials and drug approvals.
- A French member told us that a new drug for lupus (Lupuzor) should be available in Europe from 2018. Lupus affects five million people worldwide (60,000 in France alone). Lupus is an autoimmune disease, similar to Rheumatoid Arthritis, colitis, and Type 2 diabetes. It is also close to ECD, due to the symptoms of pain and it also affects the immune system.
- It was pointed out that for BRAF negative patients, a lot of the drugs that are for autoimmune diseases could be tried. [Editor's note: Many BRAF-negative ECD patients are reporting good results in using MEK-inhibitors.]
- The French member has still not had his BRAF status sorted out. The tests will be repeated in October.
- It was suggested that using Trovagene, the urine test for BRAF that is used in the trials, might give a quick and accurate answer.
- A member, who has needed to move into supported accommodation, is doing well according to his wife. He "actually went out on his own to the mall using the community bus". He has a few doctor appointments next month, and they will see if there is "any new stuff". He came back to the family house last weekend, as he had appointments on the Monday. He came with a walker, and managed to get around with it. He is now doing his own shopping for groceries and supplies, and if there are any problems, the carers will let his family know. His wife has noticed that he is still a bit unsteady here and there, at the house and on going downhill, even with the walker.

The new accommodation has been a good option, as it allows him the space he needs to live in independently, as much as possible. She does have to pick up his medications on a "semi-regular" basis. He is now about a 30 to 45 minute drive from the family house in Newmarket. He

is about 20 mins to half hour from her father in Toronto, and 45 mins to his doctor appointments in Toronto. Public transit is two hours in one direction; but, as she had discovered on the previous day, four hours for the other way.

- The poor performance of the Blue Jays was commented on.