

## **Summary of ECD Global Alliance Internet Chat**

### **04 June 2016**

12 Attendees

- A member who has been on Vemurafenib (V) for 13 months is getting weary of it. She takes a dose of 1 pill in the morning and 2 in the evening daily. Her skin seems worse, even though she stays out of the sun, and she is more dizzy. She is tired of V's side effects, and is ready to switch to Dabrafenib (D) which Dr. Diamond would like to do. She has just had a stress EKG and echocardiogram and her heart is "fine to switch". She wonders whether D would work better on her brain lesions.
- A member said that he had heard that D can have nasty side effects too, and those are different ones than from V.
- D & V have similar properties. A member who has made the switch is having no side effects, and another member on V is considering switching from V to D because of this!
- The member on D said that he didn't know how well it was working, but he feels fine. He hasn't been getting sunburnt, although he is not sunbathing! He has been outside for 15-20 minutes with no sunscreen, and no burning. He is taking 6 D pills (3+3) a day which another member thought was equivalent to taking 8 Vs, a high dose. It was said that he should be seeing a fair amount of shrinkage of any lesions, although there wasn't much there when he came off V. Just being off the V for a couple of weeks started to make him feel "funny".
- No-one was aware of any publication about using D alone on ECD, with BRAF V600E. This can make things harder, although Dr. Diamond doesn't seem to have any problems getting whatever he wants!
- A new member who hasn't started treatment yet asked whether anyone was not taking drugs for their ECD. He was told that there had been a woman from Florida on the Chat who is not on anything at the moment.
- The member who may be switching to D said that she had had another sinus infection a few weeks ago and was on Augmentin for 2 weeks. Then she thinks that she got a C. diff infection, so she started taking Flagyl. The problem was that the nurse practitioner forgot to write for C. diff on the specimen, so it was not run correctly!
- A new member said that he can still manage his pain without drugs, but he is worried that he will become depressed. He finds that he manages best with "plants". Depression was then discussed. There is, he said, a paper that links episodes of depression to the development of bradykinesia (slowness). It is the accumulation of these that cause the slowness. So, to stop getting slow, take antidepressants. He said that balance is OK and there is no dizziness. Being slow affects fine motor skills, speech, and limb coordination. "So kaput to dancing, getting out the door in less than one hour".
- A member said that she doesn't take anything for pain, but she takes Gabapentin (Neurontin) 300 mg at night, which is supposed to help neurological pain, but it is totally

non addictive. She also takes cymbalta (duloxetine), about 30 mg every day. This is an antidepressant that can also help with pain relief. She reminded us that her husband is a psychiatrist!

- We were given a follow up report on a member who started V a few months ago. He is doing well, and he sat outside in their new gazebo last week. He had to walk down the stairs, and then master some steps to get there. He is waiting to see the physio in mid June to see if that also makes a difference.
- Health insurance in the US came up for discussion. A member had had PET scans requested by Dr. Diamond, which were done in April. Her insurance BC/BS wouldn't cover the cost. Memorial Sloan Kettering took the cost and did them anyway. She appealed, but the company still wouldn't cover them, so her attorney is suing the insurance company. BC/BS is an individual policy that she has had for 34 years.
- A member is with Humana and has had few problems. Another said that Unitedhealth Group is good.
- A member awaiting the start of treatment with interferon is waiting on insurance approval. Mayo is going to mail it to her once it is approved. She was asked whether she was feeling tired, and she isn't. She power walks half an hour a day and cycles half an hour each day as well. Her eyes are uncomfortable, and she has some trouble from one of her ankles and the lower leg. She is not sure if that is linked to ECD. She had had an X-ray on the previous day.
- A member told us that his heart is affected by ECD and the doctor has said that he may implant a defibrillator. He had a stress EKG back in Oct 2015 with excellent results, but he then had a heart attack on Dec. 21, 2015 and had a stent inserted. On Apr. 24, 2016, he had a second episode and got another stent put in. His heart has two scars affecting the electric flow. They want to ensure that he is prepared to stand any heart episode. His regular cardiologist couldn't explain his case and why there were two 100% blockages in less than 3 months. V treatment had removed the pain from his tibia.
- A member really wishes that he could "get his balance back". He is trying to get walking and exercising. He has been on fentanyl for his leg pain since 2008.
- Someone asked whether some of the bone pain drugs are bisphosphonates. One said that she had been on a bisphosphonate for 6 months, but Dr. Diamond and her local doctor told her not to take it anymore.