

Summary of ECD Global Alliance Internet Chat

23 April 2016

8 Attendees

- A member has just returned from seeing Dr. Diamond. He has reduced her dose of vemurafenib (V) to a dose of 2 in the morning and 1 in the evening because she is having so many joint issues. He said that her PET, MRI, etc. shows that while the lesions are present, "they are snoozing". Hopefully, she will be able to exercise more on this lower dose. At the moment she cannot tolerate more than some swimming. In two months, Dr. D may reduce the dose to 1+1. She sees him again in August. He talked to her about going on his MEK trial, but she is not sure that her heart would handle it well. She has a family history of heart disease, and already gets chest pain sometimes.
- A member has just got home from two hours of spinning! She has had a "marathon week" of exercise with her trainer.
- Another told us that she pedalled a recumbent bike the previous week for a "slow 30 minutes" [does this mean that time slowed down, or was she pedalling slowly?!]. She managed to "sprain" her ankle, but had no falls.
- A member, who has had V and is very keen on exercise, said that when he was on higher than 2 V a day, running really brought out the side effects of V, particularly rashes. But he felt so good from the running that he would rather have dropped V than stopped the exercise. He said that, in his opinion, once the lesions and the blood are saturated with V, adding more V is not going to do much. "If everything is stable, you just have to wait for the bad cells to die."
- Another member who is on V came on. He said that he is doing OK, and his doctor has reduced the V from 3+3 to 2+2. He has been having trouble with his hands, having "lesions" all over them. He can't make a fist and finds it really frustrating that he can't grip anything. He is having a PET scan this week. He was told by another V user that a lot of these lesions will be due to the V, and not the ECD, so reducing the dose is a good idea.
Another has 4 "knots" in the palms of each hand, and Dr. D said that they were from the V. Dr. D also thinks that she may have carpal tunnel syndrome in her wrists, and she is having it checked out locally this week. Some members are having difficulty getting up from a seated position. A lift chair was suggested.
- Fun with the sun when you are on V was mentioned. A member had been in Las Vegas recently and had walked for miles under an umbrella with sunscreen. He thought that he was OK, but a few days after he was back home, he found that his face was badly burnt. He didn't have any problem in NYC, as he was always going in and out of buildings.
- The member whose husband has recently started V said that they have just returned home and were amazed by how much "stuff" there was. They have tried the new ramp and he went for a ride around the block in his new wheelchair. They live at the top of a hill so part of the walk involved a lot of work, and the other part he was coasting down. He likes the new wheelchair – he's a "speed demon" on it. This was the first time in 5-6 years that they had gone out after 6 pm and walked (and wheeled) around the block! On the day before the Chat he walked a flight upstairs... as the lift had to be recharged!

The doctors are happy that he has hit the targets that they set for him and his dose is 2+2 V.

The doctor asked if he could write with his right hand, but he is not at that point yet. He will see the dentist, dermatologist, and a local doctor this week. They are also currently dealing with a decrease in his anti-depressant medication. He sees the psychiatrist this week. He is on Cymbalta (Duloxetine). There are problems with some medications because he has some issues with his heart. When he had an MRI of his heart he was found to have masses in his ventricle. There was also some infiltration around the coronary arteries.

- We were told that Cymbalta has some good effect on pain. One member's husband is a psychiatrist and used Cymbalta to treat the pain in his bad knees.
- The member whose husband is on V, said that the V has seemed to be a great pain reliever. He was really unstable before starting V. He was weak, had problems standing up for just a short period and could not take some of the pills that he needed. He is now much stronger, has more energy to do things, and can manage his medication.
She is "taking a step forward" in going to her work place in downtown Toronto, and having her son and brother-in-law handle her husband's dental appointment.
- Members discussed dental appointments. Are there any restrictions affecting people on V? When they asked the doctor about V and the dentist, he said that generally appointments went fine.
Another member said that he didn't have any problems with dental work with V. Another said that she needs to go to the dentist for a check up, and has also had some bleeding around one molar.
- A member who has recently come off her trial drugs had a recurrence of the ECD within 7 weeks. The doctors are going to restart the medication. She was on the NIH trial of trametinib and dabrafenib. She was diagnosed with ECD in 2012, and had been sick since 2007. She has lesions in her cerebellum, brainstem and kidneys.
- Finally, a new member came on, saying that she currently only has ECD in her eye tissues and she has not started treatment.