

Summary of ECD Global Alliance Internet Chat

03 Oct 2015

7 Attendees

- A member on vemurafenib (V) asked whether others had had any trouble with their hands and fingers swelling. He "can barely use" his. He had been taking a dose of 4 pills in the morning and 4 pills in the evening, but he has taken himself off for a while, and hasn't restarted yet. His hands are still just as bad. He is also having bone pain, and food doesn't taste right. He hasn't yet talked to the doctor about it, but he will.
- Another member who has had V said that she had to reduce the dose, too. She had had swelling and joint pain, but after reducing the dose she barely had side effects, apart from some hair thinning (and this has grown back curly!).
- Another member who has had V said that she had had to go from four twice a day to two, because she had skin reactions on the second day. Now she is on 3+3, "but the V stays in your system for a very long time".
- The wife of a newly diagnosed ECD patient, who lives in Canada, told us that they have got a date for a biopsy. This will be in Toronto, Ontario next week. He has at least 7 doctors involved in his care. It is the family doctor who got things moving for the biopsy with help from the states and hopefully they will find a way to slow it all down. He has been ill for about 4 to 5 years, but in the last two years there has been a more rapid decline in his mobility. And nobody knew why. He will also have an MRI on his skull and spine, which will hopefully yield more information. She asked how long it would take to get a result. A member who had a biopsy on her leg said that it had been only a few days before she heard back.
- A member wasn't sure whether she will be going to Houston. She has room reservations, but hasn't got plane tickets. She will see if there are any seats left. She said that she always seems to have a "crazy" feeling in her head, and she is afraid that she won't feel well while she is there.
- The member who is troubled with macular edema is having a relapse, although her recent MRI showed that nothing has changed since April. "I'll take stable any day!"
- Another member had a neighbor over for dinner recently, who is a neuro-ophthalmologist. They talked about ECD and eyes but the member "didn't learn anything that I could repeat".
- We were asked whether stress affected anyone, and in what ways. One member said that stress affects her walking. If she is stressed (or in a hurry) she finds that she is more wobbly. Another finds that her vision will get worse when she is stressed. Her cortisol (a hormone produced by the adrenal glands to help us cope with stressful situations) levels used to be low, but are now fine after V treatment. Others told us that they had never had their cortisol levels checked.
- A member whose husband has been newly diagnosed asked whether patients "lose stuff" over time and not get these things back later. Her husband has been getting more symptoms over the last 5 years. He's had loss of balance and he complains about dizziness pretty much all the time. And now he is having more mobility issues. Sometimes it is a help to get some assistive aid such as a cane.

- One member told us that she gets a "crazy/dizzy-like" feeling in her head". Another gets light-headed and she also gets a pressure feeling in her head with sounds that are constant. They sound like a washing machine! Others said that this sounded like tinnitus, and that sometimes making sounds that match it helps, such as humming. She calls it "pulsatile tinnitus" and a member suggested that she might be hearing her own heartbeat. She has a lot of dizziness, but rarely falls. On the PET her leg bones are much better, but her right shoulder is "a mess" and the lesions in her brain are only stable.
- A member who uses exercise as her "second medicine" told us how much this has helped her.
- A member told us about her shoulder problems. Her right shoulder and arm hurt most of the time, and her movement is limited. She goes to the warm water pool about 5 times/week to walk, kick, and try to rehab. But, since there is a growth in her shoulder bone, rehab won't really help. She was advised to start with some light movement, increasingly doing more while she is on the V. She told us that she had walked that day inside for 1/2 mile, was in the pool for 1/2 hour, and rode the stationary bike for 1/2 mile! She has just had a rough week. She has a lesion/tumor in the head of her humerus that has grown, despite the V. She is being sent to see an orthopedic oncologist who deals with a lot of sarcoma at the University of Kentucky Med Center. She feels like she has "hit the wall".
- The possibility of intravenous chemotherapy for the shoulder lesion has been mentioned, and/or radiotherapy. She asked whether anyone else had had radiation treatment, and no-one had. She doesn't use any pain/sleeping medicine but has found that a cup of chamomile tea, and lavender oil drops on her nails helps "some". Some of her friends used to call her "Granola", because she tried to always use "natural" stuff. Now she is on V for ECD!
- Another member of the V-treated family said that he had found that a combination of exercise and low dose of V is most effective for maintenance. In fact, if he exercises but doesn't sweat, it's not as great as if he should sweat a lot. He used to have severe restriction in his right shoulder, but it has become looser since going onto V. He is now doing daily exercise with his shoulders and this is helping him get back to "almost normal". It's the best he has been in 15 years.
- A member told us that her leg bones were more badly affected on the last scan, but she has no pain. She thinks that maybe the steroids that she takes for her eye condition are having a good effect on the legs. However, she is losing her hair which is probably due to the V. Another member has lost half her hair so she has cut it very short!
- A member who is very tired since she has been on V said that if it is helping to reduce the side effects or slowing it down, "giving you a chance of normal life", then it may be worth it.