

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

**27 Aug 2016**

8 Attendees

- A member whose husband has ECD, said that she was enjoying the last of the summer before school starts again. Their youngest child is entering grade 10 -- so another 3 years to go for school. She will have to make some time for her husband's upcoming medical appts (of which there are many). He is monitored weekly, and there are a few bi-annual or yearly appointments coming up too. The hospital trips involve an hour's drive each way, and then you get to add on the time spent actually at the hospital!  
Her husband also has a wound which needs to be seen. He had his dose of vemurafenib (V) dropped from a dose of 2 pills in the morning and 2 in the evening to 1+1, because his QT interval (a measure of electrical activity in the heart muscle) became raised. The plan is for him to go back to 2+2 of V, to continue the drop in dose of anti-depression treatment, and to assess his wound. She had seen a lot of changes (not necessarily for the best) on going down to 1 and 1. On the lower dose, his balance, swallowing, use of the right hand and arm have all been affected. Going back to the higher dose will show if he can be got back.
- A member told us that he had been on the V trial for about 2 years now. He does go to the gym, although not religiously. He doesn't know if that helps or not. Perhaps he should go more often! He walks a bit, twice a day, with his dog. Before he became ill, he was a trumpet player in the Houston Symphony Orchestra. It was pointed out by another member, who used to try to play the trumpet, that "Blowing your horn is 100 calories an hour!". Unfortunately, he has retired now!
- The importance of exercise was emphasised. Members thought exercise helped V to work better. It was said that "every little bit helps". One member has to do his exercise by going up and down the stairs... as the chair lift is not working at the moment!!
- A member said that he felt that exercise is good only if you are on V or other drugs. He said that in some laboratory experiments, mice with circulating tumors (and on no medication) actually had faster cancer growth with exercises.
- A member who has been on V, and is also having problems with her balance, has started "vestibular rehab". She told us about one of her exercises. She has to try to walk down the hall (for protection, but not to hold onto), and every 3 seconds she must move her head from side to side. Another is to do the same, but, this time, to make her head go up and down. Each exercise only needs to be for a minute or so. Another member who has balance problems had been advised to try standing still, feet apart at first, then together for 3 minutes. And then to do it with eyes closed!! He used to stand and brush his teeth with his eyes closed. The automatic toothbrush ran for 3 minutes anyway, and he was not allowed to hold onto the sink!!
- Members asked about the effects of reducing V dose. One asked whether the increased skin thickness on the feet gets better when one drops down on the V dosage. Another asked how long it normally takes to feel the effects when you drop or increase the V dose. A member who has had V treatment and is now on a maintenance dose of 2 V a day, said that he doesn't have any issues with the skin on the hands and feet. He thinks that you would probably notice the

effects from changes in V dose in 3-4 days. It is a long acting drug (highly protein bound) so it takes a while to come out of your system.

- A member, who has just reduced from 2+2 to 1+1, said that she doesn't feel any different yet. She had developed bad nodules on her hands, and wonders whether they will get better. She goes back to see Dr. Diamond in December. She has a local oncologist who is in contact with Dr. D. She will see her in September for blood work, etc.
- A member came on after the Chat had finished. He apologised for missing out. He is on 3+3 dabrafenib (he had been on V but his liver enzymes became raised, so it was changed). He is feeling well but has noticed that his strength is not the same. He used to be able to lift heavy things, but now "I'm lucky if I can lift a 50-pound bag of sand 20 feet".