

Summary of ECD Global Alliance Internet Chat

07 May 2016

10 Attendees

- At the start of the Chat another new member from France came on. He is about to get a diagnosis of ECD, and is just waiting for the biopsy. He said that he will be at the Paris conference.
- Members discussed their exercise regimes. A keen exerciser said that he had been running and lifting weights, but his legs have been really tired lately. He said that he may "need to slow down my running speed"!
- One said that she did "A little bit of everything". She does walking, elliptical and rowing machines, weights, and stretching. She is going to try doing some jogging with her trainer. He doesn't come as part of the health package in Norway! She pays for him herself. She exercises for at least one hour daily. She is planning on doing a presentation again about her condition and exercise for patients and staff at the hospital, and then another one for friends.
- Another member doesn't exercise apart from swimming and walking about a mile with her husband and dog (a 65 pound labradoodle). Her joints rebel if she does much more and this is very frustrating. A few weeks ago she slowly rode 5 miles on a recumbent bike and developed a "sprain". She used to hike for hours and walk 9 miles or more without a thought.

She has recently had bronchitis and been taking amoxicillin. She asked whether vemurafenib (V) caused immunosuppression, but it was not thought that it did. She has been reducing her V, and is now on a dose of 2 in the morning and 1 in the evening, without noticing anything different. Her shoulder and hip really hurt. It is thought that the pain is due to the V. She thinks that Dr. Diamond wants to get her off V and onto a MEK inhibitor, trametinib. She sees a cardiologist soon because of her family history of heart disease. Her PETs from April 21 are OK. They are not really any worse, but not better. She has a new lesion on her sternum and some coating on her aorta. Timing of doses was discussed. She takes 2 V at 7 am and 1 at 7pm.

Another member used to take one in the morning and 2 in the evening. It seems that the drug is most effective taken before bedtime, when your stomach is not full. She is going to start taking one in the morning and two at night. She thinks that Dr. D will let her go down to 1+1 if she asks him in June. Dr. D said he was not concerned about the new lesion.

She also had an EMG (a test of the conduction of nerve impulses to a muscle) on her right hand/arm this week. She has some compression of the nerve in the carpal tunnel and sees a hand specialist this coming week. She said that she won't have surgery since it's not too bad. She wears a splint on her wrist at night.
- Another member has a lesion on his spine that comes and goes. It is not always picked up on scans, which means that it is not significant. Someone in the neighborhood of a member has written a story about her. It has been posted on <https://www.caringbridge.org/visit/janetbunge> .

- Today is Derby Day, which is really big in the area where one member lives, since it is run in Louisville, KY and most of the horses were born around Lexington.
- A member has been reading a lot about V, particularly data from people who have melanoma. He said that it was amazing to see how much fundamental work has been done on V already. He is going to see whether he can find similar data for dabrafenib (D). Ultimately, he thinks that he may use D in the long run (he is now in remission after being treated with V).
He is interested in the physiological aspects of D. He thinks that he would be ok with V, but D seems to be cheaper and working just as well. MEK inhibitors are good, particularly for diseases that would develop resistance to BRAF inhibitors. But ECD seems to not be doing that.
- "Buffs" were discussed as aids for sun protection. Two members are using them and finding them helpful.
- The trovagene urine test was discussed. Of the members who have been to Memorial Sloan Kettering (MSK), one had never used this testing, while the other had done 30+ tests in total! Fifteen of these were done during the 1st week of taking V, mainly to see if the BRAF V600E level has gone down before, during, and after taking V. He is now doing less than 5% of what he used to do (testing, scans, blood work, etc) when he was on the trial.
- A member who has pituitary involvement asked Dr. D whether he tested for low Human Growth Hormone (HGH) in such patients. He said that he doesn't test because he wouldn't replace HGH.
- We got a summary of all the goings on with the man on V whose wife comes on the Chat. She told us that he is improving each day. The other day he shocked the kids by wheeling himself to the kitchen and making his tea. The only thing that had to be got out for him was a cup, everything else he was able to get for himself! Physio will start on June 17th, which may give him confidence to use the walker more and maybe try with the cane. They have just had a meeting with the CCAC co-ordinator - who confirmed that they will keep 7 hours of time from the Community funded caregiver.
On the previous day they had a meeting with the speech therapist, who was thrilled to see that he can eat now without problems. He is still advised to "follow the procedure" such as eating dry food and wet food separately. When she saw him have a hamburger with no problem she could see that he was "fine for now!"
His mobility is much improved. They went for the walk around the block with him in his wheelchair. On the first time that he did this he was stuck quite a bit, but this time he was able to push himself to do more. His wife almost had to "give him a speeding ticket".
- After the Chat had finished a member came on who had missed the Chat because he was putting on his bets for the big Derby today, and then he had a communion to attend. He has swapped from V (which upset his liver enzymes) to D, which he has been on for the last two weeks. He is on a full dose with only little bumps on his arms (not itchy). "I feel great.", he said.
- Finally a member came on who had missed the Chat because she was graduating. She has been doing well other than some pains in her back and legs, but nothing too bad.