

Summary of ECD Global Alliance Internet Chat

01 Aug 2015

9 Attendees

- Weather was the first topic.
- Eye problems were discussed. We nearly all have some sort of eye problem. One member was born with Congenital Nystagmus, and sometimes has bulgy eyes. Another's very first symptom was double vision. They then found masses behind his eyeballs, and then did other tests until ECD was diagnosed.
- A member who has responded well to vemurafenib (V) said that his eyes were bulging, and optic nerves were swollen. He had pink eyes 24x7, and double vision. He hasn't needed to see an eye doctor recently as he is doing fine and in "remission".
- We were asked about frequency of attending eye doctors. One member was not sure whether her dry eyes were due to Sjogren's syndrome, the ECD, or the vemurafenib. She asked how often she should attend the eye doctor. Another member with dry eyes sees his eye doctor about once a year for checkups. One has an "open appointment" so he can just ring the eye doctor's secretary and get a slot. He sees his optician every year.
- A member told us that she had just had a good checkup at Barnes-Jewish. Her blood results are fine, and a PET scan showed that the disease is holding steady. She is on the trial in St Louis. She has been on V since July 1, 2014 and takes 3 in the morning and 3 in the evening. She got hives when she was taking 4+4. When she has pain, it is on the right side of her body. It is hard to make a fist in the morning. She has also been told that she has a marker for Rheumatoid Arthritis.
- A member started V in February of this year. Since then he has had "things" in almost all the bones in his body. He is having quite a deal of pain in his hands. He is having difficulty grasping things and holding onto them. A member who has already had V treatment said that he thought that a lot of these issues were due to the V. He used to have serious hand-and-foot syndrome, when he was on 4+4 V and this included pain, swelling, and losing control of his hands & feet. Also he has had a problem with his hand. Sometimes, due to the way he sleeps, he has poor blood circulation when he wakes up.
- A member who has waited a long time to find out the result of BRAF testing said that he was BRAF negative. This means that V is not for him. He is hoping that when he goes to Bethesda "they'll get my balance fixed". He had driven into town to get his Fentanyl (a painkilling medicine) the previous week. Driving was difficult. He finds that he can't take time to check his speed. He can end up in the on-coming lane, or off the left side of the road. He said that if he just drives up and down the drive, "I'm good"! Perhaps he would drive better after "a good nap". Three members said how important having a nap was to them.
- A UK member said that he has a 3 wheel electric disability scooter, which "looks a bit like a Harley" (in his dreams!!). It only does 8mph on the road, so the member who finds driving

difficult should be able to control one of those. (And, he would get to look "cool" as well! Mr. Easy Rider!! Summarizer's comment; shouldn't that be Mr. ECD Rider?!!)

- It is legal, in the UK, at 4mph on the sidewalk and on the road at 8mph. No helmet required or driver's license. Insurance is required, if you run over someone's foot you will be liable (or bash into their car!). The member has been hit by a car once, but it was the other driver's fault, so his no-claims bonus is still standing! He wasn't hurt himself, but the scooter got a bent rear axle, and smashed bodywork. At the time of the crash, he was going to the pharmacy to collect a prescription. The paramedic who had come walked up to the pharmacy for him! The ambulance had a tail lift for stretchers so the crew dropped that, pulled the "Harley" on board, and took "Harley" and the member home!!
- A member in remission had had a good appointment with Dr. Kurzrock. He has found that, as he is taking V, it is very important to have a combination of good exercises and rest, including afternoon naps. Driving is a good physical therapy session for him. One of the reasons for him coming off the V trial is to find a low V dose, or an alternative drug, for maintenance.
- A month ago some-one asked on the Chat whether there can be a change in personality in ECD patients. A carer said YES. She was sure that not all ECD patients have a personality change, but some did, partly because of all the medication that they have to take, and the pain that they are in. "We have to remember to LOVE the patient and Hate ECD". She said that she had spoken with several ECD care givers, and they all say that, at times, their loved one can be loud and hurtful. Her son, who has ECD, has said that sometimes he has no control how his words come out. But this does not change how hurtful this can be.
- A member said that he knows that he has changed a lot from a personality standpoint. It is particularly hard for his family members to deal with.
- Ataxia (the loss of the ability to control your body) has affected one member's walking, the use of his arm, his speech... among other things. Over the summer, the family has noticed a more dramatic decrease in coordination, speech and balance issues. It was said that ataxia is most easily explained as "being drunk without the fun of getting there!" It's what alcohol does to everyone, "except we have it all the time! And 10 years being drunk is a bit boring!"
- A carer said that her son's speech and balance are much better since being on V. He uses a cane for support. Another member uses a cane for support, but also walker and wheelchair if he not up to walking.
- Medical insurance, care, and medications were mentioned. A carer, whose son is on a V trial, said that he has the expense of traveling to Houston, TX once a month. But he does not have to pay for the medication. His insurance is billed every month for all the lab work and tests that are run. He has to go to Houston every 28 days. Insurance does not cover his plane fare or his hotel costs. He has Blue Shield Insurance in the USA, and "they have been wonderful to cover most everything".
- It was asked whether being on a V-trial would be less expensive than ordinary care. The trial is inexpensive if it is a trial at a convenient location for you. You must be able to afford the time and travel expenses, and your insurance must cover the trial medical cost, etc. This is not always true for everyone! However, there are a few organizations that provide reimbursements for travel and lodging for cancer patients, and ECD patients are eligible to apply. There is also the Patient

Access program under Genentech. Through this it is sometimes possible to get access to V free of charge for those who qualify. There is also the ongoing clinical trial at the National Institutes of Health (NIH) for those who qualify. They do take non-US citizens.

- Some members admitted that watching various TV Shows made them feel a bit better. America's Got Talent made one laugh. Another likes to watch Diagnose Me. On that show the people have weird diseases like her!
- A member told us that she was sent to St. Louis Barnes Jewish by her doctor at the Mayo Clinic up in Rochester, MN. She said that it was odd that the Mayo is so big, but they couldn't help her out. Everybody has been shocked when she tells them that the Mayo clinic sent her to Barnes Jewish. A member said that Mayo could have helped, but they had been presenting her with a bill of \$12,000/month!! \$55 (a pill) x 8 x 30 for V at 4+4 a day! She is on the trial in St. Louis, and feels that she is helping other people out that have the disease. Her husband says that she is "a lab rat".
- A member, who is now on 1+1 V, said that it was still working okay for her. She has not had a checkup since February, and has not had a PET scan lately. The other chatter who has had V treatment has been on 1+1 V as well, but his recent PET scan shows mixed results, and he is now back on 2+1.
- Getting social security disability in the US was discussed. ECD is on the compassionate list, but first the diagnosis has to be made. To get long term benefits, you have to prove that you are not able to work due to the disability. It was suggested that it would be a good idea to e-mail Kathy at the ECD-GA for more information about claims.