

Summary of ECD Global Alliance Internet

Chat 22 Oct 2016

5 Attendees

- Members have been experiencing the usual "Fall weather" and it is now "getting cold"!
- A member told us that she would be back in NYC in December. She will stay at the Courtyard Marriott next to Dr. Diamond's office, "so we can walk". She asked whether anyone had seen "Wicked" (a Broadway show), which she may get to see while she is there. A member commented that he "extremely dislikes" Broadway, and will only go to a show if he is promised dinner too!
- We were reminded that a member has retired, and moved to Traverse City, Michigan. Another said that she had stayed there, on Harbour Island, twice when visiting friends. It seemed a very wealthy place!
None of the doctors in Traverse City know anything about ECD. He contacts MD Anderson (MDA) if he needs any advice or information. His original cardiologist from MDA is now working at the University of Michigan, so this helps.
- A member has started to see a doctor who only does acupuncture. She has had no relief yet, and goes again in the next week. She is now down to a dose of one pill in the morning and one in the evening (1+1) of vemurafenib (V), but seems to have more dizziness and joint issues. This is why she is trying the acupuncture.
On the previous night she accidentally dropped all of her Zelboraf by the kitchen sink! But not all of it was ruined. Some got wet, but not all of them and she hopes to be able to use most of them. A member who used to be on V said that he still had a full bottle at his home. She was asked whether her insurance would cover the cost of the medicines. She has no extra pills at all and thinks that she will call the specialty pharmacy in Michigan that sends the pills and ask them what to do.
- Members wondered how much V would cost as a prescription, which depends on your insurance. For one member, his own insurance wouldn't cover the cost, so he changed onto his wife's insurance and he has a \$0 copay. When a member was on 2+3 or 2+2, the cost was about \$10,000 per month, but her insurance covered it.
- Another member has a very high copay. It actually costs him less to "fly to Houston every three months, stay in a hotel and all", than to pay the copay, which would be about \$2,000 per month. He is on 2+2 and on a clinical trial, so the dose cannot be reduced while he stays on the trial. But while he is on the trial he gets the pills for free. So he thinks that he had better stay on it! He has been on Dr. Janku's trial for about 2 years and is comfortable with this.
- There was discussion among the speakers at the conference, some who recommended to avoid stopping vemurafenib for an extended time. Dr. Diamond has spoken of one of his patients who came off Dabrafenib, and is now taking methotrexate once a week. [Summarizer's note; "I have been taking methotrexate 40mg once a week for some years now, and I'm in remission. I never had any of that BRAF stuff cos it hadn't been invented when I was really sick! It is a VERY cheap drug. My dose costs about 8\$ a month, and the NHS pays for that, not me!!!"]
- A member who has come off a trial said that he had been "getting frustrated with all of the scans".

- A member said that her 3 and 5 year old granddaughters had spent the previous night with her, and the 3 year old started vomiting at 3 am and carried on being sick every 30 minutes. Her daughter picked her up at 7 am, but the member is assuming that she will "get the virus" in the next 2 days.
She also thinks that she needs another brain MRI in Lexington next month because her dizziness is bad. Every time she looks up, (i.e., in her closet) she feels nauseous. She doesn't fall down, but does fall into things. She did see a physiotherapist for about 2 months in late summer for the dizziness and balance. The balance improved, but the dizziness got worse. She thinks that this indicates "disease", and it may be due to the lesions in her cerebellum. Two others on the Chat said that they had similar symptoms.
- Hand and finger problems were discussed. One said that he had a lot less sensitivity in his fingers now. Buttoning a shirt can sometimes be a real challenge. At the beginning of his treatment with V, he went down from 4+4 to 2+2 for that reason.
For another member's fingers, especially the left middle one, it will "sort of lock down" and she has to use her other hand to "unlock" it. She now buddy tapes the middle finger to the ring finger to keep it straight.
- A member whose husband has ECD and is on V came on. His situation is a bit up and down. They are still having to deal with the wounds on his back. He has noticed that he seems to have less control over his feet and legs, which is a new symptom. He still has falls and some issues with short-term memory. He is having a MRI and CAT scan and they will know more in the coming week. They will also find out how frequently they will need to keep visiting the hospital.
He has had to switch cardiologist as the first one was not up to the "ECD challenge", but the second one just accepts it as part of the overall situation and knows that the member is being monitored on a regular basis.
- A member said that she had seen a cardiologist back in the Spring for a stress echo and her raised blood pressure. When she asked him if he had ever heard of ECD, he told her that he had "read about it 5 minutes ago". She said that she will never enter his office again!
- Another member was lucky, in that his first oncologist had heard of the disease. He retired, but handed his case over to a doctor who was interested in rare diseases. We were told that there is an emerging ECD care center in Cincinnati. But when a member called last year, they seemed disorganized and she preferred going elsewhere.