

Summary of ECD Global Alliance Internet Chat

05 Sep 2015

7 Attendees

- A member on vemurafenib (V) has gone up to a dose of 3 pills in the morning and 3 in the evening this week after being on 2+3 for two weeks. She doesn't think that she will be able to tolerate any higher dose than this, but lesions in her brain "need more V". It was her oncologist who suggested the dose increase. A member, who has been on V for a while, said that it would be interesting to see whether she would see any difference going from 5 to 6 pills a day. His experience seems to suggest that a high dose at the beginning is most effective. After that, things seem to happen slowly and steadily over time. Even now, when he is on 2 pills a day, he is still seeing gradual improvements and he doesn't think that a higher dose would have gotten everything done at once.
Her oncologist has also ordered a Cervical MRI, and scheduled her to see a neurosurgeon. She has finally had a PET on her torso, and has a limb PET in the next week. She thinks that the doctor may have "doctor coded the first one wrong". She is having shoulder and arm issues. She has already seen an orthopedic surgeon, and thinks that she has a rotator cuff tear. She is also seeing a neurosurgeon because she is also having tremors in her arms, especially on the right.
It took 6 weeks to get her insurers to approve the PET. She threatened them with an attorney, the state insurance regulator, and now she thinks that they will approve anything. Another member said that when she has a PET, it's a full body scan. She wondered whether the member having more than one PET will be covered by the insurers for "multiple tests".
- Our member, who is a teacher, told us that this year he is teaching kindergarten, and last year he taught 2nd grade. He is feeling well, and regaining the level of energy that he had prior to diagnosis.
- A member who has been taking V for some time had told us that he would probably be going back up to 3 tabs a day from the 2 a day that he has been taking. He has decided to stay on 2 pills a day after all. He doesn't feel the need to increase. He is used to the low dose now, and when he tried to increase it, he was not able to "handle" 3 or higher. It has been about 15 months since he started the V, about 12 months on 6 pills, and 3 months on 2 pills a day.
- The member, who had lymphoma as well as ECD, has had a brain MRI and a PET. The brain MRI shows improvement. The PET result isn't ready yet.
- The ARAF positive member, who is on sorafenib, gave us information on her progress. She also has been having problems with macular edema. Her last 2 OCTs (Optical coherence tomography-examinations of her retina) have not shown edema and she is hoping that this is due to the sorafenib (also her eyeglass prescription has changed). She has been on sorafenib since February (with one 3 week break). She is still on prednisone, a steroid drug, but is cutting back on the dose each week. Her ALT (alanine transferase- a liver enzyme) is a bit elevated. The drug that she takes can cause hepatitis so her blood has to be monitored regularly.
- For one of the patients who has been on V, the only high thing on his blood test is ALP (alkaline phosphatase- another liver enzyme but this one can also come from bones).

- A member logged on from a conference that his daughter was attending. There seemed to be a connection problem, as the same message was appearing on the Chat 3 or 4 times! He was advised to go and enjoy the beach!
- Members talked about how often they had their blood tests done. Two go monthly, and 1 weekly.
- Shots were discussed. A number of members have the flu-shot, and one had the shingles and pneumonia shot 2 years ago.
- The rest of the Chat was about different health insurers. A member asked about Aetna, as he is changing to it next month. A member said that she had used Aetna at first, and "they were great. Never denied anything."
- Then a member said that she thought that all private insurance companies "have morons that answer (after 15 minutes on hold) and read the script that says, "No". Someone else added that "Then, you provide them a whole bunch of supporting documents. And their response is once again, "Not for the indication!" A member had had to wait 6 weeks to get a PET because of denial. Her oncologist called the insurers, while the member was in her office. The doctor had tried every 3 days and was hung up on. She got the approval in 10 minutes (but the member had threatened the company with her attorney the day before!). The doctor, when she got off the phone, said that her case had been "flagged" and that she would get "most anything that was ordered now". Another member didn't like the idea of being "flagged", but the member who had been "flagged" said that she would rather be known, than not known, by her insurance company. She has been on this insurance for about 30 years!
- A member told us that the whole reason that he is on a trial because his insurance didn't want to cover the medicine that he needed (his insurer is Group Health Incorporated (GHI) and all NYC employees get it free). His wife's insurance would cover it 100%! He is going to change over to his wife's!!!