

Summary of ECD Global Alliance Internet Chat

06 Jun 15

8 Attendees

- A new chatter came on before the Chat. She told us that her dad had died from ECD on the 31st of May. She is from Perth in Western Australia and when her Dad was diagnosed the family was told that he was the only one in Perth that had this!
- A member, who has fairly recently started vemurafenib (V), told us that her neighborhood had a garage sale that morning and she must have gotten the sun (even with a floppy hat and long sleeves and pants) because her lips and face hurt, and her neck is red.
She has been on V for 16 days. After the first two days on a dose of 4 in the morning and 4 in the evening, she had to quit for 2 days due to a rash. Now she is taking 2 and 2.
She has been feeling less wobbly in the last few days, but still has dizziness. She feels like the room is spinning. She knows that she has lesions in her cerebellum and brainstem and these are probably causing the spinning sensation.
- Another member who has been on therapy with sorafenib (she is a BRAF negative patient), told us that it had given her a rash and blisters on her arms, but the drug wasn't stopped until her blood pressure got out of control. She is back on it now. She used a cane for stabilization for about a month. She has her husband or sister's shoulder to hold on to if needed, and the dizziness is not constant.
She has been on sorafenib since February 3, but has taken breaks during that time. She has disease affecting her long bones and skull, but her vision is the main concern. She was on anakinra (Kineret) for 4 months and it made her feel great. It took her fevers and night sweats away, and when she stopped it the fevers came back. She wishes that it had helped eye problems because she might have been able to stay on it. In 2012, she had treatments with Cladribine and Clofarabine. These drugs "destroyed" her immune system.
- A member moved a block from her old home, in March, and her new next door neighbor is a neurologist who specializes in the eye!
- A member, who had had to stop anakinra, while she had chemotherapy for lymphoma, is back on it. She had been doing well on anakinra before she was diagnosed with lymphoma, so she is back on it to see how it is going to work now. She has a shot of 100mg each day, and she has not had any side-effects. She feels great, and the anakinra also works for her rheumatoid arthritis. She is BRAF positive.
- The member who has been relocating is now in San Diego. He has already had an appointment with Dr. Kurzrock, which went well. She wanted him to stay on 1+1 V as maintenance since she said that it's working for him, and he should still see incremental improvements over time. Also, the low dose has almost insignificant side effects.

- Current V doses were discussed. One member had had a lot of joint issues on 2+2. She thinks that this was a side effect. She already has joint pain (really bone pain) from the ECD, but this pain is different, "it roves around". Her daughter and sister say that she doesn't slur her speech as much as before.
- A member, who has just started V, gets it from the VA in Dayton Ohio. He is on a dose of 4+4 which he started on 2-21-15. He had some questions about V treatment for members who had already been on it. He has a rash of small bumps on his legs, face and neck, and some larger red blotches at the base of his neck. His sense of taste for food and drink changed as soon as the V was started. His hair is coming out. Overall he seems to have more energy and stamina than before. "Are these normal on V?"
All of these were said to have been seen in others, and at a dose of 4+4 these side effects will probably persist. We were told, by a member who has been on V, that, in his opinion, if you go with 3+3, V works just as well, and "you will have better quality of life".
- Another member taking V said that she could only tolerate 4+4 for 5 doses, before she needed a 2 day break. She went on 2+2 almost 3 weeks ago. She has more stamina already and it has dealt with the rashes and joint problems.
- For one member, her blood protein always seems to be off in her blood work. For another, the problem was that her creatinine was creeping up.
- Weight changes were compared. One has lost 25+ lbs. and gone down 3 notches on his belt!! One blamed all "the steroids" for a gain of 20 lbs., and one has gained 14 lbs. He said that he had needed the weight gain, as the ECD made him lose all his appetite and he couldn't eat much.
- A new member who has just started V came on and told us that "this drug is a miracle". He has been on V for less than a week and "everything" has been improving. He is on 4+4, and he was told that on that dose he should be seeing side effects in the next few days. He hasn't had any yet. It is going to be hard for insurance companies to deny the V drug for ECD in the future! He goes to Sloan Kettering for his treatment. He lives in NYC, so it is all very convenient.
- Finally a member left a message that she hoped we all had had a good week, and that the week to come would be good, too. She has been having some bone pain and a few breathing issues, but her "main problem" is depression. She still hasn't been able to find what really helps, and hasn't had much support from her family.