

Summary of ECD Global Alliance Internet Chat

21 Feb 2015

9 Attendees

- A member left a message for us all. She has been doing “pretty well” apart from a little bone pain. After her injection that day she had 8 shots of Kineret left, before she tries going without them. Her doctor is hopeful that she will be fine without the Kineret, and may reduce or even stop some of her other medication.
- A member who has been on vemurafenib (V) for 14 months, told us that she has started reducing the dose. She is now on one pill in the morning and one in the evening. She had a lot of bone pain when starting it, but never had any issues with blood pressure. There was a lot of activity in her legs, but her arms were fine. She has not been troubled by any rashes. Her hair thinned, but she has gotten lots of curls now. It used to be straight!
- A chatter started a drug that is a “cousin” of V, just 2 weeks ago. This has been raising her blood pressure, and she has to have a second drug added. Her doctor told her to stay on two of the new “V relative” daily until next week. She has some bone pain, especially in her thighs, but no rashes or hand-foot syndrome (although this is on the list of possible side effects). She has started on a low dose with the intention of building it up. Her PET scan does not show activity in the orbits, but she still has big issues with her vision. She is going to try to use ice. She has one of those eye masks that she keeps in the freezer.
- One of the other members taking V said that a dermatologist had said that it was good to get rashes, because it means that the V is working! He had developed a rash, worst when he was on 4 + 4. Now it is mild. He did lose his eyebrows, but he “didn't have much hair to begin with” so hair loss has not been a problem. He was able to tolerate 4 + 4 of V for 4-5 days. This was also the time when he had the biggest improvement in his condition, particularly the eyes. He won't ever take a dose that large again. His eyes are good now, and the tumors are not active. Although he does have to ice, or chill down, his eyes from time to time. Sometimes he just runs cold water over his eyes for a few minutes. When he uses a cold

compress, this could be 5-8 minutes. He advised against anyone applying ice directly to the eyes; it would be too cold.

- Another member, who had taken V, didn't lose any hair. He developed pancreatitis from V when it was started, so he had to back off, and then restart at a low dose, and then build up. But the V did not work for him, although he was on it for a long time. He is now on another trial drug. The only name he has for this drug is Ixg818. He thinks that it is a "distant cousin" to V. He feels better on this, but is extremely tired. Since he started the new drug, his walking has gotten better.
- Another Chatter came on who has just started V. He is on 4 + 4. He said that he was doing well, but he was "stuck in the cold and snow" in Ohio! A different member said that it was in the 70's in Florida, and the next day was forecast for 80 degrees!
- Members discussed the monitoring schedules that they were keeping to. Weekly blood monitoring was done at first. The member who has no active disease now, is having check-ups every 6 months.
- One Chatter had already registered for the conference scheduled for Houston, TX in October, and others said that they wanted to get there.
- A new member came on and introduced herself. She lives in Kentucky, and is currently waiting for the result on the BRAF mutation study at NIH. She told us that she had been misdiagnosed in the past, and was still "in a bit of denial" that she has ECD. She will be back with us when she has her BRAF result. She asked whether any other members lived in Kentucky, and was advised to contact Kathy Brewer. If Kathy has your permission and gets permission of others, she can give you the e-mails of ECD patients near you.
- After the chat had ended a new member came on. She was diagnosed 4 months ago, and lives in Southern California. She is 49, and has 2 children, aged 16 and 13.