

Summary of ECD Global Alliance Internet Chat

08 Aug 15

10 Attendees

- A member left a message to say he was too tired to be on the Chat. In the UK it starts at 2200 hours, and he had been up very early the previous day to go and "muck about" in an "artisan bakery"! (Summarizer's note; a lame excuse, if ever I heard one!)
- A carer told us that her son had persuaded her to come to Houston, and she has registered (like a good little girl). Her son was on Gleevec and doing well. But the doctors decided it was time to go on to the vemurafenib (V). He sees Dr. Janku in Houston. He has a lot more energy now that he is on V.
- The member who has relocated to San Diego said that he was very tired and resting a lot. He is now back in Minnesota for a while. He had a good appointment with Dr. Kurzrock. They are trying to do a few rounds of genetic testing this month, to see if there are other mutations beside BRAF. It's likely that ECD could have come from multiple mutations, in addition to just BRAF. These tests will be probably most important for the BRAF negative patients.
- Our woodworker had entered three projects in the county fair at the beginning of the week. And he had helped his grandson make another one, and his great-grandson make another two projects for the fair. He had gone there this week to see how they had all done. They had entered six pieces and got six first-place blue ribbons! He was "well pleased"!
- The member troubled by macular edema (as well as ECD!) said that the prednisone doesn't seem to be working well enough to take it away, and the sorafenib (which she takes for her ECD) is not helping her eyes (so far). She has been off and on the sorafenib since February. She was off it for almost a month due to side effects. Kineret had helped with her symptoms, like fever and chills, but did nothing for her eyes. She has signed up for the conference, but is not sure yet whether she will be attending as she is just "not feeling that great". But there are still a couple of months to go until Houston.
- The member whose husband has had recent treatment for bowel cancer told us that he was doing well. She doesn't have any recent blood counts from herself.
- A member on V (dosage was prescribed for 4 in the morning and 4 in the evening since February) said that he had been having a lot of pain in his feet and hands. He can't close his hands properly, and in the mornings they are very stiff and painful. He tries to help the pain by rubbing his hands, and he takes the occasional tramadol (a painkiller). He asked whether anyone else was having these kind of problems. He believes that it is due to the drug and was just wondering how long they lasted. It was said that "if it hurts often and bad then, maybe, a lowering of the dose might help". Another member, who has been on V, told us that he had had hand and foot syndrome. In addition, he had mornings when he lost control of his left hand. He has read some publications recently that describe "Dupuytren's contracture" as a possible side effect in some patients who were on V for months. He said that the onset is very similar to what he is feeling, and similar to the description given by the other member.

- A member, who has done VERY well on V, said that his only problems were tiny calluses on his foot and bad sun sensitivity. He recently had PET scans done and all the tumors have decreased, especially those in the brain. The brain lesions had shrunk by about 80% in the 2 months that he has been on V! The masses in the orbits didn't shrink as much, (about 50%). From the outside, the eyes "look good though". He had had huge masses behind the eyes, and he had had that jelly-like substance in the corner of his eye. He had had orbital lesions but they are not showing up now in the PET, or MRI.
He had gone to Lake George for a couple of days, and had to wear a sweatshirt with the hood on while driving up there! He wondered whether tinting the windows in the car would help.
- A member on sorafenib (a "cousin" of V) asked whether any of the members on V found that it made them feel a little dizzy. The sorafenib makes her head "feel crazy and dizzy". She guesses that it could be because "that's where the disease is".
One member said that he gets a weird feeling sometimes when he is bent down and gets up quickly. But it only lasts for a few seconds, and he used to get that feeling before he started on the medicines.
- Sleeping positions were discussed. There has been recent coverage in the press about this topic. Certain sleeping positions are supposed to help the brain get rid of some harmful waste products. There an article regarding the sleep pattern -- <http://www.medicaldaily.com/lateral-sleeping-position-influences-clean-brains-metabolic-waste-products-halts-346618>
- A member told us that he has found that his symptoms, particularly related to his eyes and brain, get worse if he sleeps on his back vs. laterally. Three of the chatters said that they also sleep on their sides.
- A member who has been on V said that his take regarding V side-effects was that when your ECD is very active and advanced, and you are BRAF positive, you don't see many side effects. However, some of the side effects may become more visible once your ECD is more stable and your dose remains high. However, by that time, you really don't get much advantage by being on high dose anymore.
- A chatter came on towards the end who lives in Indiana. This member had ECD diagnosed at 18, having been ill since the age of 14, and now the doctors say things are stable. Treatment was initially with interferon and then Kineret, and is now only on a few pills for pain and depression.
- After we had finished a member came on. Saturday chores "had called" and so she hadn't been able to join us.