

Summary of ECD Global Alliance Internet Chat

11 Feb 2017

11 Attendees

- Not all chatters that entered the chat room contributed.
- The first chatter was on the chat for the first time and is from India. He has ECD with a lot of pain. He wanted to know whether there was anybody else from India. [Editor's note: There are a total of 3 ECD patients from India registered with the ECDGA.]
- Another member new to the chat asked whether there were any resources for financial grants or donations to help a family/individual with ECD, to pay for past medical costs. [Editor's note: Unfortunately the ECDGA cannot assist individuals with medical costs. However, now that ECD is considered a cancer, the organizations set up to assist cancer patients may indeed be in a position to help ECD patients as part of their mission.]
- Weather was discussed. The snow has hit the USA good and proper!!
- A member asked whether anyone had experienced neuropathy. This can occur after chemotherapy. A member said that she'd had some neuropathy, but this was diagnosed before her chemotherapy.

This member had had a brain MRI that week, which showed no change. This has been the result for the last year and a half. She wonders whether the lesions that are showing are just "shells", or is her brain not responding to the dabrafenib (D). Her last PET was in mid December. Dr. Diamond then changed her from vemurafenib (V) (which was giving her joint problems) to D and tried an increased dose to work better on her brain. She doesn't think that her brain is "lighting up" on the PET, but the MRI seems worse. PET is used to define whether one's ECD is in remission or still active. It was said that maybe the scar tissues are difficult to dissolve back into blood circulation. And that this would be necessary for them to clear from the scans. It's very hard to get protein bound drugs through the blood-brain barrier because they tend to stay with the blood plasma. Both V and D are very highly bound.
- A member, who has a history of depression, said that he had not been given V because of its effects on mood. He is using Kineret injections, but with all the injections that he needs, he gets itchy legs. He is also troubled by "dizziness", and said that his feels like his "head turns" [this symptom is called vertigo].

A member who has swapped from V to D said that she thinks that her mood is better. She is also more dizzy, and will see an ENT in two weeks.
- A member is going to have a brain perfusion scan. His wife asked whether anyone had had one of these before. Nobody on the chat had had one. She said that what will be the biggest challenge for him is the rule of "No tea for 24 hours"!!