Summary of ECD Global Alliance Internet Chat
04 Jul 2015

7 Attendees

- A UK member left a message hoping that things were going well for everyone. He mixed up his national holidays with his pumpkin and tea, but the thought was there.

- The member who has been doing well on vemurafenib (V) is now “absolutely awesome”. “It's been like a RedBull energy drink so far.” (This probably doesn’t feature on the drug’s data sheets. Perhaps he should notify the manufacturer?)

- Another V user has been pretty tired this week. She is on her 7th week of V. A user of V said that he had been tired since Day 1, and so he doesn’t don't know whether the V is making it worse or not.

- The “awesome” guy has now got almost normal eyes (they were bulging). He is still on a full dose of V and finds that “Sunburn is easy to get”. He has learned to wear sun block even if he is just walking from his car to the store.

- Wearing a medical mask was suggested, just like they give away at the entrance of a clinic/hospital. We were told that it is almost impossible to protect the lips with sunscreen, unless you wear a veil! The SPF Chapstick was said to be good, but not as good as a medical mask.

- A member is due a brain scan at the beginning of next month. This should show how the V is working. She is on a dose of 2 in the morning and 2 in the evening. A member, who has been through all of this, said that she should see improvements. His experience was that if you start feeling better and better, then the scans should be getting better as well. (But the opposite is not always true).

- The member due for the scan said that this week has been her worst in a while. Her feet hurt on the toes and balls. Her shoulders really hurt, too. She has managed to get to the inside pool 3 times, “just to keep moving”.

  She doesn't know whether this is due to the V or the ECD. She had had some trouble with this before V. It was said that if the V is the cause, then the locations of the pain tend to come and go. She said that the location has changed (except for her shoulders which always hurt).

- Exercise was discussed. A member thinks that regular exercise is very important when you're on V. He feels that the drug is more effective if you're exercising. Two weeks ago, he mowed the entire lawn, when it was cloudy. It had felt good. He doesn’t know the exact lawn area, but it takes about 30-40 minutes to mow.

- One member is trying to walk a half mile/day or so. She is dizzy so she doesn't hold onto the leash of her 65 pound dog! And she always walks with someone.

- The member, who is relocating to San Diego, will see Dr. Kurzrock for a second visit. He will be having a couple of PET scans before that. While he was on the MSK trial, he was having 2-3 MRI or CT/PET, etc. every other month. He found this "way too much".

- A member, who was at NIH in April, is going to ask about a PET with the brain. At NIH, something showed up in her lung, but no one knows what. It was said that it is a good idea to do PET scans to see ECD activity.

- Our ARAF (A-Raf Proto-Oncogene, Serine/Threonine Kinase) member is planning on going back to Memorial Sloan Kettering (MSK) sometime in September. Her macular edema was better this last week and she is hoping that this is due to the Sorafenib working. The Optical Coherence Tomography (OCT) showed improvement, but her eyes seem to be blurrier. She wonders whether the Sorafenib can make symptoms worse if it's working, like V causing pain?

- A member taking Anakrina, is still doing well as far as she knows, but Medicare only allows 3 PET scans a year, and she had one in January and April checking for cancer (she has just finished a course of chemo for lymphoma).

- Skin problems were discussed. If you are on V, your skin needs to be closely monitored -- especially if you are on the higher doses. One member has found many little growths since starting V. She guesses that this is a side effect. A member has one wart that she needs taking off because it gets so irritated. She has had some other skin lesions, but no blistering.

- Another V veteran told us that he is going to ask the dermatologist to take a skin biopsy as a spot is really bothering him. He is going to go back to MSK just for a dermatology visit. He doesn't have any blisters due to ECD.

- A member had skin lesions that were biopsied on her legs, they looked blistered, but were really filled with fatty histiocytes. This was how the ECD was diagnosed (along with femur x-ray and brain lesions). She hasn't had eye problems, but since starting on V, she has had to put drops in her eyes just to get them to open in the morning. They burn a little through-out the day. If she didn't have the issues with her eyes, she wouldn't even know she had ECD! "It is so bothersome."

- The "veteran" has red eyes and eye irritations, both due to ECD, and dry eyes. He is in remission from the ECD, but they are not going away. Perhaps this is a combination of V's side effects, and some pre-existing symptoms.

  He suggests using a warm compress before you go to sleep and when you wake up. Use eye lubricant drops to supplement this. He has found both cold and warm compresses useful. A cold compress, or just cold water running on the eyes, helps reduce irritations, while warm compresses help open up your natural tear glands to lubricate your eyes. A lot of the time, when you have a hard time opening your eyes, it's the lack of lubricating tears.

- For one member, pain in the rest of her body has been more bothersome than her eyes. The last couple of nights, she has taken a tiny dose of Vistaril (which is an antihistamine) just to sleep.

- For another, her leg pains had been diagnosed as fibromyalgia. But the doctors think now that maybe it was never fibromyalgia, and now she doesn't have that pain.
  It was said, "At some point, you just have to accept that some of these symptoms aren't going to go away, and learn to adapt and live with them."

- Colored spectacle lenses were mentioned. A member had said that she had issues with bright lights, and also going from outdoors to indoors. Her eyes don't seem to adjust, and sometimes she can't see people's facial features. Someone said that he likes to wear an amber lens when he is not wearing regular glasses. This helps him adjust from computer to room lights to outside seamlessly.

- Towards the end a member got on after trying for nearly an hour! He said that "This 'puter needs serious wk" and he's right!