Summary of ECD Global Alliance Internet Chat
27 Jun 2015

10 Attendees

- A new member asked "what is V?" ["V"-Vemurafenib (marketed as Zelboraf) is a B-Raf enzyme inhibitor.] Her husband has just finished his 2nd 5-day treatment of Cladiribine. So far he has had no real changes. He still has a big bulging eye with no sight, and is unsteady. His pituitary is largely affected also. He attends doctors at UCLA.

- A member, who has done VERY well on V, said that the "V" drug is Vemurafenib and is given to patients who test positive for a BRAF gene mutation. He started taking it on June 2 and now feels "completely normal" again.

- A new member came on whose fiancé has ECD, and is BRAF+. He has been taking V for almost 18 months now, and hasn't been able to tolerate the 2+2 dose, mainly due to pain and "feeling crappy". He has learned to live with the skin issues and hair loss. They wonder whether or not this could be a drug interaction problem. She asked whether anyone was taking V who is also taking Flomax/tamsulosin?

- At one time during the chat session there were just 3 chatters, all on V. One had started in February, one has recently moved and come off a V trial, although he has moved to San Diego where Dr. Kurzrock is now based.

- One member who started V at the beginning of June is taking 4 pills in the morning and 4 in the evening. He has had no side effects (yet). Regarding his symptoms, he feels "almost normal". His eyes are much better, but still "not looking 100%". A member, who has been on V and also had orbital masses, said that the eye symptoms may take a while to fully go, as the orbital masses have to shrink first. And, even if they do shrink, it will still take some time. The member giving this advice started V last May. When he went back to Mayo in November, his ophthalmologist told him that his left eye had receded (moved backwards into the eye-socket) by 0.5cm. He told us that he was "feeling great!"

- The members discussed the changes in the taste of food and drink when on V. This may persist, but will get to the point where you get used to it (like stopping sugar or salt; horrible at first, but gradually the new taste becomes the norm, and you can't go back).

- A member told us that he had recently had some imaging work done. He needs a couple more doing, and then he will get the results. He has an appointment fixed when he can discuss what's going on. A member said that the imaging team should be able to tell you radiology results within a day or two.

- A member, whose symptoms have improved incredibly on V, asked whether there was any research that shows tumors return after they have shrunk. Another member had heard of flare-ups after 5-6 months off V. But he is not sure whether it is the same tumor or new ones. “Can you restart V?” was the next question. This is exactly what the "LOVE" trial is trying to find out. You have to have been on V for over 6 months, and be in remission before you can go on that trial. The understanding is that most patients have not developed a resistance to V.

- A member said that he knew of a patient who is on LOVE now. After 2 months, she is seeing some rash coming back, at the same locations where ECD used to be. It is not showing up on PET yet. It will take time to see whether it is a flare-up.

- The LOVE trial is intended to see the long term effects of V after a patient has stopped using it. You can enter the study when you have seen stable results from the V, and want to stop taking the pills. You just have to go back to the trial center having the same ways/schedules as when you were on the drug. The only difference is you're not taking the V!

  The member who has moved to San Diego is no longer on the trial of V at Memorial Sloan Kettering (MSK). He is now seeing Dr. Kurzrock at UCSD. He is taking 2 pills a day of V “off label”. After discussing his case with Dr. K, it was decided that “it's probably not a good idea to be off of it altogether, not right now anyway”. He is going to be in NY in July, and is going to go to MSK, just to see the dermatologist to check his skin. His plan is to use the doctors at UCSD for his ECD care, go to Mayo for his eyes, and to MSK for his skin.

- Another member with eye problems asked who he sees at Mayo. He sees a Dr. Garrity, who has seen a few patients, and can definitely provide good insights. From an overall treatment standpoint, he would recommend Dr. Kurzrock.

- One member had been doing well on Kineret. This was stopped when she was diagnosed with lymphoma too, and needed chemotherapy. Now that that is finished, she is trying Kineret again.
- A member told us about his current treatment. He takes fentanyl, interferon, clonazepam, and testosterone. He said that his wife “is working on getting us back to NIH”. He still doesn’t know his BRAF status.

- We were told that our member, who has a special form of tandem bike, has topped 100 miles for the month, cycling with her husband. She has problems with her walking balance, and her vision is virtually all gone, but she has the leg strength to pedal. Her husband rides in the usual position, and she has a seat in front. The gearing and the chains are “really something to see”.

- We were told that roughly half of the people with ECD have the BRAF mutation. Some members had heard that some BRAF-positive patients may not respond to V.

- A member said that before he started V, his balance was "horrific". Dr. Diamond had told him that if he had a beer, then he would be stumbling and slurring. He decided that it wasn't worth having that beer. That is why he is visiting the wineries but just eating olives, cheese, and bread! He will be returning to MSK in early July.

- One member, who was not on the Chat, has been taking 1+1 V as maintenance for a while. She was one of the very first ECD patients to go onto V, and is doing well. She has been at a rehab center for nearly 3 weeks. She has been doing tougher walks than those she did last year, bike riding 6 km everyday on an electric bike, and water exercise.

- We were told that Dr. Diamond is planning on attending the conference in Houston this year.

- A member was asked about her schedule for seeing Dr. Diamond again. He hasn't said when she should return and she hasn't heard from him, either. She is still taking the Sorafenib (a drug being tried in BRAF- cases) and her local oncologist is monitoring her.

  A return of her sense of balance was mentioned as a hope by one member. "Being able to drive again would be great, too!"

- The chatter whose daughter has ECD said that his latest problem is migraines. Weather changes can be murder, and he has to make sure that he gets enough sleep. He wonders whether there may be some other triggers for the migraines that he hasn't yet discovered. He won't be at the conference in Houston this year. It's "not in the budget" and his wife will NOT fly anymore. His daughter (ECD patient) and her husband will be there. And, maybe a brother and girlfriend and sister of girlfriend too!!

- As the summer is starting in the Northern Hemisphere, the subject of alcohol was raised. Firstly, a member asked whether there was any known link between alcohol and ECD. Answer came as there are none. One member's oncologist had told her once that a little bit wouldn't be an issue. She has now gone into remission, so that advice may change!

- After the Chat had finished, a member came on. She apologized for missing us. She had been at the zoo in Louisville with her sister, husband, daughter and 3 little ones!!