

Summary of ECD Global Alliance Internet Chat

16 April 2016

9 Attendees

- A member came on from Nepal!
- A new member, who left us a message last week, came on to tell us that they were still at the Mayo Clinic in Rochester, NY. They have found that, apart from having ECD, there is a cancer in the thyroid. The thyroid gland was removed about 3 weeks ago. This has delayed any treatment for ECD.
- Members commented on the ease with which they get sunburnt, and mentioned various hats and scarves that they use to protect themselves, as well as using lip balm and SPF lotion. One member has found that she tolerates the sun much better now that her dose of vemurafenib (V) is down to 1 in the morning and 1 in the evening from 1+2. She still burns, but not nearly as much.
- A member is seeing Dr. Diamond this week. She thinks that she may have her V dose dropped from 2+2 to 1+1, or be put onto another drug, depending on her scan results. She has been on V for almost a year and every time she tries to exercise "another joint is hurt."
- A new patient came on who was diagnosed with ECD at the start of this year and lives in Miami, FL. Her first PET scan showed uptake on the long bones, liver, aortic arch and brainstem but her doctor (at the time) had no clue as to what was going on. She went to the University of Miami and was diagnosed within a few months. One of the radiologists saw her scans and guessed it could be ECD, and a biopsy of her tibia confirmed that it was. Her main symptoms are neurological. She has lesions on the brainstem and that's why her doctor felt the combination of Tafenlar (Dabrafenib) & Mekinist (trametinib) would work well for her. She has balance issues, slurring of speech, etc. She started treatment about 1 week ago and is tolerating the medications. She is not on a trial. The drugs have not done much for the neurological symptoms yet, but she has only been on them for one week. She has noticed that her appetite has improved and she doesn't fatigue as much. She has had a PET scan (12/2015) and, most recently, a bone scan (last week).

The doctor at UM prescribed the combo and then had to work with her insurance to gain approval. She doesn't have to completely avoid the sun, but has to use sunscreen and protect herself.
- A member said that he was surprised to see BRAF+ ECD patients getting dabrafenib and trametinib easily these days. Despite there being a lot of good data, people still have trouble getting V authorized.
- One member is now on just 2 V a day and doesn't have much in the way of symptoms anymore. He is not yet planning a break from the V. Another member said that she had not seen the doctor since September, and doesn't know whether a break is planned for her.

- The member who has had problems with one of her shoulders, said that she still has the fracture but rehab has “done wonders”. She doesn't have to see the orthopaedic doctor anymore, and has just one rehab session left. (She fell again while in NY, but didn't hurt her arm although she landed on it!) Her doctor wants to switch her to Trametinib but her insurance doesn't want to cover it.

This member also has significant problems with macular edema. She told us that if anyone is looking for a good retina specialist, she has found a great group that doesn't have much experience with ECD, but are willing to learn, and they also focus on research. They have really taken an interest in her case and welcome new ECD patients.

- A member has been told that there are some appearances on their scan that suggest that there might be lesions appearing. She wonders whether they are just "shells" of the old lesions. At this point in the Chat her husband brought the mail in, and her insurance company has authorized the MRI and CT that Dr. Diamond ordered. There was no word on the PETs!
- A member who had been on V found that her hair thinned, but then came back curly. Another member, who has been on sorafenib, has also got the “Shirley Temple” look.
- Members spoke about changes in body shape since being on treatment. One eats a lot less, but her torso and stomach seem bigger and her legs smaller. Another has problems, but these are due to the steroids that she needs to take for her eye problems.
- A member told us that she had had her daughter, son in law, and their 3 little ones (6, 4, 2) with them for two weeks while they sell their house (moving to another one in Lexington). They are also fostering a newborn baby boy. She said that “We have a full and chaotic home right now”.
- A member had his first bone scan early this month. It showed some activity mainly on the spine. This has come and gone over time on PETs and was not surprising.
- Exercise was mentioned. One member runs a mile in 15 mins on a treadmill, lifts weights, and does leg weight lifting for 20 mins. On the previous day he had walked for 3 miles on Las Vegas Boulevard after working out in a gym. He did own up about taking a taxi back to the hotel! Another said that she does walking, spinning, rowing machine, weightlifting, and stretching!
- After the Chat a member came on whose husband has recently started V. They are in the midst of getting ready to move back to Newmarket -- and getting the house ready. Including building a ramp for his new wheelchair. He had had some sinus problems recently, and she mentioned a site that people might find useful. <http://www.hammacher.com/Product/77024?s...>