

## **Summary of ECD Global Alliance Internet Chat**

### **30 Jul 16**

7 Attendees

- A member was having to use a "My Very First Keyboard" designed for little folk, with great big buttons. He apologized for any slow typing!
- Some members discussed whether they were going to Paris. It was a 50:50 split. One couple going, the other stating "too much crazy stuff going on in Paris".
- A member said that he was still in remission, and just taking a weekly dose of methotrexate.
- Our "gallivanting" member has returned and had a brain MRI. This was unchanged. Her brain lesions had not shrunk, they were just "sleeping" said the doctor. Her blood work was good, except for her lipid panel. Her total lipid level was 372! So, she went back on the statin.  
Her legs don't hurt, but the joints do, and she is as dizzy as ever. She had the MRI done locally because her insurance will cover it. They won't cover the PET that has been ordered by the doctors who are treating her ECD. However, Memorial Sloan-Kettering Cancer Center (MSKCC) have said that they will cover the cost of the PET if the insurance will not. Members were pleasantly surprised that the hospital were prepared to do this!
- A member told us about her journey to hospital appointments. She leaves from Lexington for the airport 3 miles away and gets to New York's LGA in two hours. She gets a cab and arrives for her scan by 9am. She sees the doctor at 3pm, and doesn't even have to spend the night there. On the next visit her twin sister is going with her.
- There was then a discussion about places to eat near the hospital! We were told that we should try to grab lunch consisting of a chopped salad and soup from the place right on the corner. Another said that "I always get a bagel across 53rd from the old Jewish guy!" And the last recommendation was Treehaus on 3rd Ave and 53rd St. It was said to be "Very affordable and a good portion".
- The member who has been swapped from V to dabrafenib (D) is doing well, with little in the way of side effects. Just "a little keratosis" on his arms and legs. The ECD was on his brainstem and affected his gait, balance, speech, and eating. After about a month on V he said that he "really didn't have those issues any longer". He started to see improvement with his eyes in 5 days. He was then on the max dose of V for 5 and 1/2 months.
- Skin issues were discussed, particularly hard knots like scar tissue under the skin, which some have had. One said that she had had ECD skin lesions which settled down after starting on V, but these lesions were "new and different". These knots have only come up in the last few weeks. They vary in size from a pinhead to almost a centimeter.  
Another member said that she has these lesions too, and for a very long time. Hers are all about a centimeter in size. The taking of a biopsy to see what they are was mentioned. Her local oncologist had no answer last week, and she doesn't see the dermatologist until after she next sees Dr. Diamond. She will ask Dr. D about a biopsy. She would like to be able to just "ignore them!".
- A member said that he had a lump on his chest, and he wondered if this was part of the ECD. We were reminded not to "just blame everything on ECD".

- A member who has just started taking tramatenib (T) said that she was having some severe pain in her lower back/pelvic area and did not know what to think. It started 3 days after starting a new drug, and she thinks that she will have to have it checked out, if it doesn't go away soon. She already has to have an echocardiogram periodically while on the T, and have her eyes checked for some serious side effects.
- Some members talked about having seen a Dr. LaCouture. He has probably seen many many patients who are on V, but also has treated patients with Trametinib.