

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

### **19 Nov 2016**

9 Attendees

- A new Chatter left a message. His daughter has ECD and has problems with "dizziness". She had this before the ECD diagnosis. The doctors kept telling her it was vertigo. [An ex-doctor (who has ECD as well!) writes, one of the main difficulties around this is the use of the words: vertigo, dizziness, giddiness, lightheadedness and feeling faint. Doctors are taught very specific meanings for all of these words used to describe symptoms, but patients often use the same words, but they don't have the same meaning as fit with the way the doctors use them. To the doctors, vertigo means the sensation of spinning, like when you get off a roundabout. The word "giddiness" means the same as vertigo. Lightheadedness and feeling faint are used by doctors to describe the feeling when you quickly stand up, or have been standing still for a long time (for instance-soldiers on parade). "Dizziness" is a word that nobody has the same meaning for, so it is best never to use that word. Vertigo/giddiness is caused by the part of the inner ear, that controls balance, misbehaving. Lightheadedness or feeling faint happens when your blood pressure falls, and so not enough blood is being pumped up to the brain.]
- A member came on complaining that the doctors were bleeding him every two or three visits to prevent his blood from "getting too thick". He said that this was due to "cholesterol". [Same old ex-doc again! Cholesterol doesn't make the blood thicker, but other things can, so it is probably something else that they are looking at.]

The visits are causing problems because he doesn't drive anymore, his wife is "zapped from training" and his family is "disappearing from the face of the world" and so he is "running out of rides"! He has been on interferon for some years. It is keeping his illness under control, and he gets it "for free", so he won't be switching to vemurafenib (V). His blood pressure is regular. He uses interferon 3 times a week, fentanyl for pain, bupropion for depression, and clonazepam for Restless Leg Syndrome. He also takes some supplements. He thinks that he will stick with this regime.
- A new member came on and asked whether anyone had experience with taking cladribine (2CDA). He took it from January through June and is now in remission. One member has had it [that was me folks!], but wasn't on the Chat that night. It did not get him into remission.
- A member said that she has "decided to become my own primary doctor" and "take the bull by the horns". Even though she is now down to a dose of one pill in the morning and one in the evening of V, her joints are worse. She had a cortisone shot in her left shoulder two days ago for rotator cuff issues, and will have trigger finger release surgery on her left middle finger on Dec. 5th.
- Another member had bad joint pain when on 2+2 V, but got better when she reduced the dose, especially when she got down to 1+1.
- The patient with the joint pains is also having problems with her blood pressure (BP). She said that even when it is taken on both arms at the same time, she has different top readings! She is going to a cardiologist who has treated her before in a few weeks, and then goes back to see Dr. Diamond (and have a PET/CT) on December 15.

- Another member takes metoprolol (a beta blocker) twice a day for his BP. He is still on 2+2 of the V. Another takes a beta blocker at night and a calcium channel blocker in the morning. She also takes gabapentin (Neurotin) to help the pain, but since "dizziness" is a side effect she only takes it at night. She is trying to decrease the dose. She had spoken to the staff at the cardiologist's office on the previous day, and had been told that she couldn't get an appointment for 6 months! When she explained about the illnesses she got a slot for Dec. 8th!
- The wife of a member with ECD came on to tell us that he is "doing ok". He will be having some follow up appointments this week and in the next few weeks to get some results from a recent MRI. His CAT scan came back and showed that his kidneys are improving. The wounds in his back are also getting better. The skin doctor took a sample of "pimple like" skin from the front for biopsy. Balance is still difficult for him. He depends on the wheelchair - walker combo.
- A member said that he had been indulging in his "kitchen passion". He was so caught up in it that he "almost did not feel the pain so much".
- Another new chatter came on and asked whether anyone had experience with methotrexate (MTX). One member had had a bad experience with it when the doctors thought that she had something else! Another has had a good result [Me again! I have been taking MTX for some years. I am in remission now and take 40mg ONCE a week. I never had V since it wasn't invented when I was ill!].
- This new member said that he has been taking interferon 3x per week for 10 months. It was very helpful for his chronic cough (although the cough is now back). ECD has affected his lungs, kidneys and aorta (with crust buildup). His bones have been ok with very little pain, but low energy and shortness of breath.
- Our French member said that he sees the specialist every 3 months at the moment. He is taking Kineret. From time to time he does have pain in the lungs, but knowing that this is ECD means that he doesn't worry about it being pain from his heart.
- Members talked about having copies of their scans. One would like to see the pictures of his legs. He never has! One member said that she has copies of all her scans, but has nothing to load them on to. She keeps them so she can share them with other doctors, if needed. When she had her first femur x-ray at Duke, the doctor looked at it with her and exclaimed "that is very abnormal!". At last someone was listening to her concerns and could see it on the x-ray.