

Summary of ECD Global Alliance Internet Chat

08 Oct 2016

7 Attendees

- A member asked others what types of vitamins they take. She takes D, C, B12, and CoQ10 and is on a statin for her cholesterol. Nobody else contributed their regime.
- One said that he just takes treatment for diabetes insipidus, and Anakrina for ECD. He has just returned from the hospital. He was at the conference in Paris, and had found it very rewarding. We had been shown how the disease affects our bodies, and how they can respond to certain drugs.
- A member told us that she had just been hospitalized for a week, and already it seems that her symptoms are back. She has been off of chemo for two weeks now. She had been on vemurafenib (V) at a dose of 4 in the morning and 4 in the evening. She has been suffering from lymphedema and was "swollen all over" while her legs and feet were weeping. She asked whether anyone else had, or has, an issue with lymphedema or fluid retention. Her most recent angio showed tissue softening around the heart so V appears to be working there. There are no ECD "experts" where she lives. She sees Dr. Barry Berman, and is in the process of getting her doctors to confer with Dr. Diamond and others.
- Another member said that she had been on V for 18 months, but her dose has been decreased to one in the morning and one at night. She is more dizzy and tired, and her bones are beginning to hurt. She wonders whether her dose at the moment is too low.

She has lesions in her cerebellum and brain stem. She only tolerated 4+4 for two days, before going down to 3+3 for about 10 months. Her PET scans and brain MRI have been stable, so Dr. Diamond has decreased the dose. She has not had issues of edema or fluid retention.

She has some "coating" around her aorta, but no symptoms. She did have a lesion in her lung, but that has gone. Her symptoms come from the brain and bone lesions.
- Insurance issues were discussed. One member has had her BC/BS since 1983, but they have balked at physical therapy issues. She has quit talking to them and got her attorney to do it instead! Her husband is a psychiatrist, so depression is a household word. In fact, he oversees a chat once a month through a closed facebook page called "ECD caregivers Chat". He coordinates conversations with ECD caregivers. [Editor's Note: any caregivers interested in joining this group are encouraged to email support@erdheim-chester.org and ask about the caregiver's group.]
- For one member, her insurance (Medicaid) decided to drop the specialty pharmacy that supplies her V. This was Express Script and apparently she is now going to be set up with Magellan.
- Another member uses Diplomat Pharmacy in Michigan as the specialty pharmacy that sends her V.
- We were warned that if we think that we have insurance problems "wait till you get Medicare".
- A member, who comes from Minnesota asked about the Paris conference. She particularly asked whether sinus involvement in ECD had been discussed. One of the doctors is intending to classify ENT disorders present in ECD, with a final goal of improving the early diagnosis of ECD. A member said that she gets a lot of "tinnitus type" problems when she is tired. Her nose runs a lot, although the fluid is clear.

- The member from Minnesota gets seen by a haematologist at Mayo, and Dr. Ghobadi at Barnes Jewish St. Louis.
- After the Chat a member left us a message. His wife had had her wisdom teeth taken out, and he had gone food shopping ("...again").
- After the chat someone came on to say it was their first time and they were not sure if joining live chats is possible because the timing doesnt work. They were diagnosed with ECD in July and have been on V for a week.