

Summary of ECD Global Alliance Internet Chat

05 Nov 2016

10 Attendees

- Before the Chat started, 2 messages were left. One new member asked a familiar type of question; "How long should it take before you are treated for ECD?". [Editor's note: This is really dependent on each patient's situation. The [ECD Referral Care Centers](#) have committed to getting patients treated quickly, based on the patient's situation.]
- A longstanding member told us that she had had her gallbladder removed that week. It was "not functioning" and her doctor informed her that this led to her not being able to eat. Since it has been removed, she has been doing much better. She is already eating larger meals than before the surgery.
- A new member came on; he is 58 years old and was diagnosed with ECD in January of 2016. (He is BRAF negative.) The oncologist in Denver treated him with Interferon for six months. An MRI showed no change in tumor size. He went back east to Boston and went onto a clinical trial. He started using Cobimetinib (a MEK inhibitor) just twelve days ago, a dose of 3 times a day. So far, the side effects are limited to just a small rash, and a need to find a bathroom quickly.
He was having symptoms three months prior to the diagnosis; but, like many of us, he was having minor symptoms up to fifteen years ago. He felt "completely healthy" up to a year ago. When the illness hit him, he thought that he had had a stroke. He had to give up his home, leave everything, and move to Denver where he was finally diagnosed.
At the moment, his entire family is staying with relatives in Massachusetts. He has been "in and out" of a wheel chair six times. Just before he started the Chat, he was able to walk about a quarter mile or more. Today is a good one at the moment, but he can change at the drop of a hat, because he has a lesion at the base of his brain, and tumors in his neck and spine. The ECD is also affecting his heart.
He finds that even typing and looking at the computer is hard for him. Just two years ago he worked as an engineer, and looked at a computer fourteen hours a day! In the next week, he will go back to Boston to see Dr. Jacobson to see if he will be kept on the new drug. He will also be seeing a cardiologist and have a heart monitor "installed" to see what his heart is doing. The disease has invaded the right side of his heart. He may be starting to have heart failure, and does get short of breath sometimes. He has had eighteen doctors so far since January. He said that he will be glad when he "only needs to see just one".
- Another member said that he had been diagnosed in 2015. The ECD had been attacking his nerves, and he had a "bad time" for a few months, although his life is fairly normal now. He was first treated with vemurafenib (V) for a while. He was then switched to dabrafenib (D) because V was messing with his liver.
- Another chatter was diagnosed in April of 2014 at a Mayo Clinic. He was Braf positive, so he got into the clinical trial for V. V has been "amazing" for him, and he is now down to 2 V's a day for maintenance.
- Members talked about the importance of having a healthy diet. (Although the new member seeing Dr. Jacobson did say that he had asked the doctor for a prescription for carrot cake!!)

- And then the subject of constipation came up. One member said that he was having "a hard time" using the bathroom. This is the situation for two or three days, then it goes the other way for about two hours, and then he is constipated again. A member who has ulcerative colitis (UC), as well as ECD, suggested that he should take 1 tablespoon of psyllium husk powder or metamucil mixed in water after each meal. He has been doing that for many years, and finds that it works very well. It's his secret to control UC. You can also mix it with orange juice, or any drinks that you want to, as long as they are not warm or hot.
- A member came on who is from Nepal. His wife was diagnosed with ECD three and half years ago. She has had surgery to a brain tumor (Pineal gland), and a pericardiectomy (opening of the pericardium, a "bag" of tissue that surrounds the heart). The doctor advised Interferon, but due to its high cost and side effects, they decided not to take chemo. Till now, she has only had symptomatic treatment, and has been stable.

The ECD caregiver group was suggested and also the ECD Global Alliance website. Kathy Brewer (support@erdheim-chester.org) would be a good contact to make, and these sites would be helpful as well.

 - <http://erdheim-chester.org/care-centers/>
 - <http://erdheim-chester.org/treatments/>
 - <http://erdheim-chester.org/studies-trials/>
- Braf inhibitors were mentioned (vemurafenib and dabrafenib). A patient should attempt to find out whether they are BRAF positive or negative, as these treatments are limited to BRAF positive patients. BRAF inhibitors are not available in all countries. However, patients can discuss availability with their doctor. BRAF negative patients can discuss with their doctors the availability of MEK inhibitors as possible treatment.