

Summary of ECD Global Alliance Internet Chat

4 Mar 2017

6 Attendees

- At the start of the Chat, a member said that he enjoyed the Chat itself and reading the summaries. He had been to see a gastroenterologist and gave him a fact sheet from the ECD website. (Find this resource here: [Medical Brochure](#)) The doctor then said, "Oh, I already know what it is.(!!!)". The doctor had never seen anyone with it, but had read about it and rattled off a description! This was the first doctor or pharmacist that this member has met in six years who had any idea.
Another member said that she gives every doctor she sees (so far, more than a dozen) a short description of what she has been through, her current meds, and her current doctors. They have all really appreciated this. She believes those who tell her that they don't know of ECD. The ones who tell her that they have read about it (5 minutes ago) and act snotty, she smiles at, and leaves (never to return).
- The member whose husband has ECD said that she was travelling to see friends, and he was staying for a short while at a nursing home. He was in good spirits when she left the previous week.
- A member who has swapped from vemurafenib (V) to dabrafenib (D), said that he was doing well. He had had hand/foot syndrome so bad that he could not walk. He was diagnosed 8 months ago. He sees Dr. Go at Mayo, and has seen him twice. He will go again in June for a visit, but they converse "all the time" by email. He lives in Chicago and is 58 years old. He had been a runner all his life and has been unable to run since last summer. "ECD has really been the devil."
He has pain in his right humerus and shoulder, painful knots on the tendons in both hands, and pain in the soles and heels of his feet. He was very ill with pericarditis at one time and still has some trouble with pulmonary and cardiac infusions.
He was on V for months, at a reduced dose, but the hand/foot condition syndrome warranted a change in medicine. He has been on D for just five days, and his only side-effects have been a mild headache. He is taking 150mg twice a day.
- Another member had also had the hand/foot syndrome when he was on 8 V a day, and another said that she had not had the syndrome, but had had horrible calluses on her feet, especially below the fifth toes. She has to have custom orthotics now.
She changed from V to D and is taking 100mg of D twice a day. Dr. Diamond stopped at this dosage, because he figured that she would never make it to 150mg. She tends to get all the side effects! She had a neck MRI a week ago and sees three doctors this week to try to discern if her shoulder issue is from the shoulder or if it is from the neck.
She saw an ENT last week about her dizziness. Despite the last brain MRI showing no change, her dizziness is worse. ENT said that she does not have vertigo due to her ears. "Must be the brain!!!"
- The member who got hand/foot syndrome while on 8 V a day, said that on 2 V a day, he doesn't seem to have any significant side-effects to warrant a switch to D. His diagnosis was precipitated by him having bulging eyes and double vision. His pink eyes just would not go away and these symptoms have now resolved.
- It seems like people are not having issues on getting authorization from insurance companies to get onto D.

- The member from Chicago said that his local oncologist really did a good job on submitting the justification. It was denied the first time, but she submitted journal papers and a narrative on why V did not work for him.
- A member said that her shoulder/humerus pain is on the left and that she has knots (Dupuytren's contracture) in both hands. She had begun to notice lumps in her palms and a hand ortho made the diagnosis. She also had a trigger finger which he released with a bit of surgery. As long as the Dupuytren's does not cause her fingers to draw up, "I'm OK" and she "just lives with it". She does not take any pain relieving meds, because she reacts to any narcotic.
- A member said that, for him, the hand/foot issues all came due to the V. Dr. Go seems to think the hand/foot issue will dissipate on D.
- A message was left by a member after the Chat. He could not attend the Chat because he is off to the hospital where his father is still an in-patient.