

Summary of ECD Global Alliance Internet Chat

07 Nov 2015

11 Attendees

- A new member introduced herself. Her husband has had ECD for 6 years. He takes Vemurafenib (V), and so far this has held the disease back.
- A member told us about a fall he had recently. He was walking from the parking garage to work crossing a street downtown, and maybe not quite picking up his feet enough. He went to the emergency room to get all checked out, and all was good. He is now on the mend. He lives in Houston and goes to MD Anderson, and sees Dr. Janku.
- A member who goes to Mayo, and is on the V trial, came on. She is going back soon for scans and blood work. Her primary doctor is just back from having a heart valve replacement. She missed him very much since he knew all her health history. In 2014, she was in the hospital, and made "such an impression" on one of the doctors, that she has written 2 papers for Mayo on ECD. Next year the doctor will be moving to Little Rock, Arkansas.
- A member, who is changing doctors to Dr. Diamond at Memorial Sloan-Kettering (MSK), was asked whether she had a date firmed up yet. She hadn't, but has been phoned to say that all of her scans had arrived. She is in such pain in her right arm and shoulder that she might beg to see another orthopedic this week. The motions of her arm/shoulder are restricted, and the pain is present whether she tries to move or not. She gets into a warm water pool 3-4 times/wk. just to keep the arm moving, but even typing can hurt.
- The areas in her brain that are affected are "stable" but haven't gotten smaller. She thinks that Dr. Diamond will be "a good person to see". She had been on a dose of 3 in the morning and 3 in the evening, and dropped herself to 1+1. After 5 days, she began to work back up to 3+3. A member wondered whether the pain is a side effect from V.
- One orthopedic doctor said that she didn't have a rotator cuff tear (even though the report on the MRI said that she did). Another orthopedic oncologist said that there was nothing to do surgery on, and he gave her an order for physiotherapy. She does have a clump of histiocytes (or something) in her upper arm/shoulder area. Neither of the orthopedic doctors had ever heard of ECD (and didn't care to find out anything about it!). It was suggested that she "needed new docs" and she agreed.

Exercise was discussed. Every time that she exercises on the bike in the gym, or walks, she ends up with irritating joint issues. She can't work out to the point of sweating, because of joint pain rather than fatigue. But, she is also on a couple of different meds for high blood pressure. One is a beta blocker, which keeps her heart rate around 70 beats per minute. And it is hard to increase this. She is hoping that Dr. Diamond will decrease the dose. She tires very easily (although not so much when exercising) and easily gets dizzy.
- Side-effects from V were mentioned. One member has just had hand and foot syndrome, another had hand and foot syndrome, rashes all over, liver damage, and drowsiness when on the higher dose.

- A member who has been taking V for a long time, is now down to 1+1. She reduced to this dose about a year ago. Now she likes to get "really sweaty" everyday, walking on the treadmill for 30-45 min before work. She says that this has "done wonders" for her, although she has some concerns about running because she doesn't seem to pick up her feet high enough. She was not this active when on a higher dose. She found that it took a lot of hard work to be able to get her pulse rate up while exercising. Her trainer (sounds more like a torturer) kept pushing and pushing her. Now she manages for herself. She takes no medicines for blood pressure.
- Another member, who has been on a V trial, said that he was now on 2+2. He was originally on 4+4 and had a lot of skin lesions, mostly on his neck and face. Lowering the dose helped a lot, and now he has none! He thinks that he was fortunate to get a clear diagnosis early on.
- A member, who has been through treatment with V, said that there was a point when he was on a high dose and not exercising. When his dose was lowered to 2 pills a day, he didn't see any side effects. But when he started running and sweating a lot his rashes came back, even at the low dose of V. But he told us that he feels much better when he combines a low dose of V with a 20 min running regimen. He has found that he needs "to sweat" to feel better. He has tried walking for 40-45 min but this is not nearly as good as running for 15 min. He guesses that maybe his remaining lesions are shrinking because of this.
- Some members discussed their times at the Bethesda and Houston conferences, and reminisced about meeting each other.
- Another member spoke about exercising. He also has some trouble picking his feet up and said that he would be in "big trouble" if a car was coming at him. He has started swimming regularly. He said that it was "amazing" how much better your balance is in the water. And it doesn't hurt to fall!!
- After the Chat had finished a woman came on whose husband had been diagnosed with ECD on the previous day. She said that they were scared, but relieved "to have his illness have a name".