

Summary of ECD Global Alliance Internet Chat

19 Mar 2016

10 Attendees

- A message had been left in the Chat Room during the week by a new patient. Just starting out on the ECD road. She has a number of appointments to go to and scans to have done.
- Another message left early was from a member who was having a birthday. So he wouldn't be on the Chat!
- The Chat started with a member telling us about his treatment. He has been on vemurafenib (V) for quite a while. His liver enzymes had become significantly raised, and he was asked to stop V. He is now taking V at a dose of 2 in the morning and 2 in the evening for two weeks, and then having a rest period of two weeks. The liver enzymes are near normal now (one of them is normal!).
He has also had a "sinus issue" brewing up, with headaches and slight bulging of the eyes. The doctor suggested that he take steroids for a few days. He has never had sinus problems before last winter. He gets a nagging headache and glossy eyes with a little bulging, wateriness and sensitive to light. He doesn't get any visual problems.
- If you are on V there are some antibiotics that you must not take. There are also restrictions on other medicines, such as painkillers.
- Another member, who has not been treated with V, has been "trying her best" to get out and walk dogs everyday (she does this as a job) as well as trying to finish school. She is doing well generally. She is going to Purdue Calumet in Indiana to earn her bachelor's degree in business. Her trip to school only takes 10 minutes. Someone said that "Going to class is like going to the gym...it's got to be close by".
- A member who has just started V said that it was being kind to him! He is walking better and his knees are a lot less painful. He has got the use of his right arm and hand back. He is now more stable on his feet and his gait is better. Even though he had a fall on the previous day, he was able to roll over and get up by himself. It was asked whether PT or OT help to get further improvements, as well as V. He is not doing OT (apart from doing what he's told to do at home!). An OT is visiting in the next week to show him "the right way" to do things.
It was said that improvements continue for one year, but then go more slowly. It varies between people. It is probably best to focus on doing a new challenge each day.
- A member who has been stable on interferon for some time has had a trip to the doctor. They don't want to "fix what ain't broke", so he is staying on Intron 3 times a week.

- The member who has just started V is having to cope with the sun sensitivity. His brother has bought him a "bandit outfit" to wear outside. He thinks that the neck scarf should be black and the mask red, then he can say "The Shadow knows!"
- Another V user has learned to accept the sun sensitivity. He accepts that he can't do landscaping outside because of vemurafenib and has landscapers now.
- A member told us that she had been on a hike that day. She had got a little over a thousand feet above sea level. She recently had a holiday in Florida, where she "Did Lots of shopping, walking and swimming everyday". She was OK in the sun using SPF 50 and wearing sunglasses and a cap. There was "no bikini or sunbathing". After 10 days her body started itching.
She was diagnosed in 2011, and started V in 2014. She has had a physical therapist for about 4 years, and has been exercising with a personal trainer for one and a half years.
She finds that exercise helps her to feel good. Sometimes, she says to herself "I want to exercise ECD away!" She also suggested keeping a diary to write down new things that you are able to do. Try to do new things, and overcome fears of not being able to do stuff, because eventually you will manage. She said that she still falls a bit, but she just gets back up and tries again. She walks around by myself, and has walking sticks for longer walks outside. Her PT helps to stimulate nerves in her feet and works with her hips.