

Summary of ECD Global Alliance Internet Chat

03 May 2014

7 Attendees

- We got off to a slow start. Only 2 members came on in the first 15 minutes. Then “things started happening”!
- Our new member asked some general questions. Did we all have bone problems, how is our balance? Do we all have lung problems? How is it to take medicines for ECD? He is not on any medication as yet.
- A member said that he needed to use a walking cane or a wheeled walking framed most of the time.
- The new member asked about how the medicines affected patients, and was told that, for the other member, taking the medicines wasn't too bad. He hadn't had all the tiredness that the other folks talk of on Interferon. It just didn't work! He has been ill for 9 years, so he is not expecting a miracle cure to turn up. Steroids had helped when his lungs were very bad, but weren't a cure. He had spent 9 days on a ventilator, and 3 months in hospital. His lungs must be OK now. He plays the trumpet (for fun) and manages to make a fairly horrible (and loud) noise!
- A member asked about back pain. She is taking multiple pills but they are not really helping. She is also trying acupuncture and heat and ice therapy but nothing seems to help. She has been scanned and this has shown only irregular bone marrow, but the pain keeps increasing. Otherwise she is doing well. Still taking medicines for her dizzy spells, and still getting a bit dizzy. The docs “can't figure me out”.
- For one member, his illness had started with feeling unsteady when he walked. He also developed double vision. It took 18 months for the diagnosis. He had a brain scan to try to help in diagnosing the cause of the double vision. This showed swellings behind his eyes. And it all rolled on from there. His back became painful and he just took pills. When his lower back was scanned, it showed that he had had compression fractures in his lower spine.
- A member has recently had an MRI scan of his arm, but hasn't had any result yet. He also saw an eye doc who was concerned about his field of vision, because he is not picking up images in some areas. He is going to be seen again in a month. He is seeing another doc about prism glasses. A member said that he had prisms in his glasses to correct for double vision. They work well as long as he remembers to wear them! Otherwise, “there are 2 of everything. People all have 2 heads!!” Another member said that she wished she saw people with two heads because she “wouldn't be able to stop laughing”.
- Members talked about dogs, and their ability to “talk with their faces”. They seem to tell stories with their looks and don't need words.

- The new member said that he lived in Turkey. There are no doctors, listed on the ECDGA site, that are in Turkey. He has been given more information by Kathy, and will be contacting some of the doctors listed. A member said that she "will not be a big help to you because I am new to all this, about 1 1/2 years. In my bones, mostly". It is also in her lymph nodes but medicines are helping. She sees Dr Janku at MD Anderson in Texas. Dr Janku is working on a test for BRAF with Trovogene. She tests positive. It is a test done on a urine sample. Details were sent out by the ECD Global Alliance this week. This e-mail also has contact info about clinical studies.
- A member who has been diagnosed just recently came on. She had been in hospital having tests until the previous day! Her disease is not too bad, and she feels "very fine". Her maxillary bone is affected, and she has pain in her legs, arms, fingers, feet and thoracic bones. The scans only show disease in the maxilla. She has been told that she has atypical disease! She starts on interferon shots, once a week, this week.
- One of V's successes came on. She had been out that evening (it was evening in Norway, where she lives). She had been diagnosed in 2011. Her nervous system and skeleton were affected. She started Vemurafenib in Dec 2013. Bad balance and stiff legs were making walking hard, but she is slowly getting better. She feels good, and is working out every day to keep her body moving. Her Docs are "very positive".