

Summary of ECD Global Alliance Internet Chat

03 Jan 2015

5 Attendees

- A message was posted before the Chat started saying that one member might not be able to chat because he was expecting some neighbors for a visit.
- A member told us that she has been on Anakinra injections for 4 months and will be getting MRI and PET scans this month to see if this has helped. She has tumors in her skull and orbits. In 2012 she was placed on Cladribine. After two months, the doctor decided to switch to Clofarabine, another chemotherapy drug. This severely damaged her immune system but all her tests since she was diagnosed, show that she is stable. She seems to have more symptoms now, but guesses that the tests will show how she is doing. She asked others about cladribine (2CDA). One member, whose daughter has ECD, was placed on 2CDA and she has no active disease at present.
- A member has Lymphoma, as well as ECD, and has now finished her chemo for the Lymphoma. She had a PETCT the previous day and meets with the "Lymphoma Dr." this week, and then Dr. Janku who is supervising her ECD treatment. She has not yet been restarted on Anakinra. They need to know whether she will need further treatment for the Lymphoma first. She is hoping that the chemo has taken care of it, and should know this week. Her last PETCT scan had "excited" both her doctors about what they were seeing, presumably because things were looking good.
- A member told us that his treatment was interferon and he has been stable since 2009. He has double vision and poor balance. This happened when he started interferon, although his sight improved for a while, and then worsened. This also coincided with the beginning synthroid treatment (a thyroxin replacement).
- Another member said that her main complaint was her vision. Lesions in her orbits have caused her to have macular edema. Her vision is blurred.
- A member summed up by saying that although 2 of the Chatters were stable and one "in remission", they still have a lot of symptoms. She told us that every time that she has a new symptom, she is afraid that "the disease is getting worse".