

Summary of ECD Global Alliance Internet Chat

17 Dec 2016

13 Attendees

- A new member asked whether others had trouble with fluid retention in the body, including in the feet and legs, and if they had, could they please get in touch. He said that the doctors just shrug and say that they don't know. He has also noticed that over the past 8-12 months, his ataxia-like symptoms have been more pronounced and he needs a walking aid to get around.
- A member told us that he had tried to get help with dry and sore eyes. He has had problems for about three years. He tried a method posted online and it has provided some relief. You grate a potato, and put it on your eyelids for 15 minutes. He has done this for four nights, and each time he has had days with much less soreness.
- A member came on who had not been in the Chat room for the past two years. Welcome Back!!
- One of the members online said that he had been chatting for one year, and received the definitive ECD diagnosis in August. He has just received some results from Paris that say he has ECD lesions in his brain. He is going back to see Professor Haroche. He has various pains, but the most troublesome are in his hands and he is also sometimes dizzy. He still drives without any problem, but he is sometimes afraid to get out of the car if someone is parked next to him.
- A member told us that she was well with no pain or fatigue. Just her balance and her stiff legs are a problem, but she is still driving with no problems. And another said that she was not able to drive, "but my husband is retired" which presumably is code for him being "available" for chauffeur duty at any time!
- Others mentioned how they were getting on with preparations for the holidays. Parties and family gatherings all around!
- A member had missed the Chat because she was on route back home, after a visit to Memorial Sloan-Kettering in NYC. Her PET scan was better, but she doesn't know about her MRI. Dr. Diamond will discuss the scans with the radiologists, and decide whether or not to alter her medicines.
- Finally, after the Chat had finished, a member came on to apologize for not turning up. That day he had had the family Christmas party at the house. This had involved a lot of preparation, food shopping, etc. He said, "If I don't make it next week, have a Merry Christmas. Enjoy and have a restful week!"