

Summary Of ECD Global Alliance Internet Chat 01 Jun 2013

6 Attendees

- A member came on before the Chat, to tell us that he had to go out for some garden supplies. It is very hot in the Mid-Atlantic region of the States. It is the 4th day of temperatures in the 90's, so it's officially a heat wave.
- A member said that she is doing better, walking a little better and has more energy. This member has recently swapped from interferon treatment to low dose naloxone. She is having an MRI, of her spine, soon, and is anxious to hear, if there are any changes from the last time

This member lives in Norway and was asked whether she will be able to see the total eclipse of the sun in 2015. In the UK, cruise firms are already taking bookings for trips up to Norway, and beyond.

- A member in the UK told us that an English lady with ECD, who lives 50 miles south of the member's house, is coming up, to Leeds, to see the Doctor involved in the member's care. Afterwards she is going to stay with the member, and his wife, overnight, before driving back south. This will be the first time that the UK member has ever met a real ECD patient! All other contacts have been "virtual".

She's not very happy with her treatment, having lots of leg pain. She hopes that the Doctor, that she is coming to see, will have some new ideas. She is a printmaker and spends most of the year on a Greek Island.

- A member is hoping that the rain, in her area, will let up, as it seems to cause more pain in her sprained ankle, and back, and all her joints seem to hurt. This member is going to the hospital, this week, for her treatment (an infusion), and for a CT scan of her lungs. She is interested to see if there has been any change.
- Having talked about X-Rays and scans a member told us that he had once managed to set off the metal detector alarms at a French Customs Check. He had a small trumpet in his suitcase that his trumpet teacher had lent him, so that he could practice while on holiday (fat chance!!). The customs people wondered if it might be full of naughty drugs! They got one of the guards, to give it a blow in the security area. He played trumpet himself, and he said it was OK!! The member's wife apologized to one of the guards, for all the trouble, and the guard said that it was all OK, and had been "very amusing"!!

- Two members came on late into the Chat. One had just ended a family visit. The other apologized for missing the Chat last week. He had been ill, and confused, with a fever, but this is now better.
- A member has been having some difficulties arranging the CA trip. Luckily, a friend knows her way “around the airlines”, and will help to sort things out. This member has a visit to the oncologist, this week, so he will have something to report next week.