

Summary of ECD Global Alliance Internet Chat

14 Feb 2015

7 Attendees

- A message was left for Patient Zero who was on the chat last week. He is not getting the chat summaries sent to him. If he sends his contact details to Kathy (support@erdheim-chester.org) at the ECD Global Alliance website, she will put him on the mailing list.
- A member who has been on vemurafenib (V) for over a year and has greatly improved, said that she has been out walking 4 times this week. She is ready for a "longer walk tomorrow"! She has also started warm water exercises with a group once a week, and is enjoying this.
- The lack of other chatters was put down to it being Valentine's Day. "Maybe all are out."
- Then another chatter arrived. She lives on a Greek Island most of the time. The Greeks have just had a general election, and it looks like there is going to be a fair bit of political turmoil there. She goes back to England for her medical care. She visits the same doctor that two other members see. Her next appointment, in March, is the time slot next to that of one of the members! So they will be sitting next to each other, complaining about the doctors running late probably!!
On her last visit, three UK members met up at a hotel for lunch-The inaugural meeting of the Northern England Chapter of the ECD Global Alliance.
- A member from the Philadelphia area said that it was snowing and freezing, with blizzard conditions up the coast (Boston). Weather experts in the states are saying that the US has just finished the warmest January in history.
- Members discussed the re-use of greetings cards, and admitted to recycling Birthday, Christmas, and Valentine's Day cards!
- The father of a member, who lost most of her vision due to ECD, told us that he fears she is losing the little sight that she has. Another member is troubled by macular oedema, and this is affecting her sight. There was a day this week when she could see the faces pretty clearly on TV, and she thought that this was an improvement, but it only lasted a day.
- It was agreed that "Acceptance is the hard part" for all of us. Everyone has their struggles, but our struggle is one that is confined to a very select few. At least we have some great doctors trying to find a cure and better treatment options.
- One member told us that she has already signed up for the Patient & Family Gathering Houston!

- There was some discussion about the number of guests that you could take with you. A member had seen that you were only allowed 3 guests. She would like to bring her husband and two sons, but one just got married and his wife might want to come as well. That would make 4 guests instead of 3. This question has to wait for an answer. (Staff Note: The solution for this is to register for the 4th member separately.)
- The member who has lost most of her sight will be going to Houston with her husband. This will be a challenge. Her father said that it would be a very expensive venture for him and his wife, as she does not fly and trains are very pricey.
- A member came on who has just restarted Anakinra. She had been taking methotrexate (another form of chemotherapy) for her Rheumatoid Arthritis, and cannot take this as well as the Anakinra. They are hoping that the Anakinra will work for both the RA and the ECD.
- A member came who had missed the chat. She sent us best wishes for Valentine's Day. She said that she had been doing pretty well, other than a few pains and some headaches lately.