

## **Summary of ECD Global Alliance Internet Chat**

**08 Nov 2014**

12 Attendees

- Although a good many members did log in at some time, quite a few did not make any comments, and a number came on when there was nobody else to chat! There were also a number of new members who logged on.
- A new member logged on seeking information. Her 31 year old nephew has just been diagnosed, and his disease is mostly in his eyes.
- Another new member logged on for her first time. She lives in Albuquerque, New Mexico, and wanted to join the Chat. She was enquiring about the start time.
- A member posted that he would be missing today. He turns wood as a hobby, and was attending the artistry in wood show, which he has been looking forward to all year.
- A member told us that she had been seen by the primary doctor who watches over her ECD. The doctor thinks that the member may be in remission! The doctor asked her to go back in January to check her symptoms. If she is doing well she may try taking a break from Anakinra, to see how everything goes. She also saw her neurologist who said that she was doing the best he had seen of her, and he has been seeing her for 4 years.
- A member came on and asked whether "anyone else's balance going south". By then he was the only person online.