**Summary of ECD Global Alliance chat held on Saturday 31st October 2009**

Number Present: 9

- A patient reported that their recent course of chemotherapy (cladiribine) seems to have resulted in an improvement. Their lungs have improved and the leg pains have gone.

- A patient had been stopped by police whilst driving and was required to undergo a breathalyzer test (the result was zero). The patient explained about his condition to the officer who said that he would spread the word amongst his colleagues. It was discussed that it may be useful for patients to carry some brief information about the disease and the information on About.com had been used by some patients. This lists ten possible symptoms of the disease and gives a brief explanation. One member mentioned that the source of information on ECD on this website was the ECD Global Alliance! Two patients on the chat mentioned that they were still driving, although one only did short journeys.

- The tee shirt project is progressing. Six boxes were mailed today.

- One patient had not been able to obtain interferon for the last three weeks, partly due to insurance issues. This patient has been experiencing severe itching and hot sweats.

- One member is working on a project to produce Christmas cards to sell as a fundraiser.

- One patient has suffered from a sore knee this week, which is limiting their activity. It seems that the muscles tear very easily when doing a stretch. It is thought that the underlying cause is ECD and/or drugs for treatment.

- A caregiver who suffered from cancer of the appendix five years ago is having tests for liver/kidney abnormalities.