Summary of ECD Global Alliance chat held on Saturday 13th November 2010

8 Present:

- One patient has recently suffered from a MRSA infection. An operation was needed to clean the affected area.

- One patient has recently been suffering from a chest infection and is on a course of steroids and antibiotics.

- Fundraising initiatives were discussed. One member has been trying to organize fund raising activities at a local school but has had a disappointing response from school staff. One member mentioned that some friends have an annual charity fundraising party; friends are invited and asked to make a donation to a given charity.

- One patient has recently been told they will receive a VA pension and some additional help from the state.

- A patient has been told by their endocrinologist that they may need to start taking insulin to control their diabetes.

- There was a discussion on the issue of balance, with at least four patient (who were on the chat or represented on the chat) having balance problems. Several patients use canes/wheeled frames/scooters to help them with balance and improve their mobility. ECD involvement in the cerebellum is likely to affect balance; visual problems may also adversely affect balance.

- Several patients have experienced heart involvement. One patient had an MRI scan which showed ECD in the atrioventricular groove. One patient has had ECD in pericardium, heart tissue and around the aorta, at one stage there was 1700cc fluid surrounding the heart. The patient improved after treatment with six cycles of cladiribine last year. Another patient represented on the chat had had a very similar experience and had also benefited from treatment with cladiribine.