

## Summary of ECD Global Alliance chat held on Saturday 21st March 2009

### 8 People Present

- One patient with lung involvement said how they found the use of portable oxygen units helpful in continuing with their normal daily life. The patient has a meeting with Dr Bauer shortly, who is based in Rochester, at the Mayo clinic. Dr. Bauer has been given some information on the group.
- One patient outlined how ECD affects them i.e. inflammation around the kidneys and aorta, also in the brain in the pituitary gland and cerebellum. The patient described how there was no increase in the inflammation in the year prior to being prescribed interferon, at 9 mill units/week, which was the first medication used to treat the ECD. The patient has recently been tapered off the interferon as it was thought that it was having little effect and the patient was suffering from significant side effects. The patient has regular CTs and MRIs and the inflammation has not progressed in two years. This patient suffers from numbing and tingling in the fingertips (not toes) and Raynaud's disease has been mentioned as a possibility. The fingers turn white. It was thought that other ECD patients have also experienced this problem.
- The volunteer who does all the work on the ECD Global Alliance website was warmly thanked by all present.