

Summary of ECD Global Alliance chat held on Saturday 23rd October 2010

7 Present:

- One patient reported that their lung function is worsening at present and they require increased oxygen levels.
- A patient is currently in hospital in intensive care. They developed thrush as a complication of chemotherapy and produced secretions and which have caused difficulties with breathing. Prayers and messages of support were passed on from the group to the patient and their family.
- Five patients on the chat (or represented on the chat) gave a brief summary of their history. Dates of diagnosis of ECD ranged from 2004 to 2008. It was agreed that the lengthy period of testing prior to diagnosis (which is the experience of most ECD patients) is an extremely difficult time.
- The next chat will be held on Saturday 30th October at 3pm EST.