

Summary of ECD Global Alliance chat held on Saturday 3rd July 2010

9 Present:

- One patient asked whether anyone else with ECD had ever been diagnosed with polio. No-one else had, or had heard of any other ECD patients being diagnosed with polio. This patient had polio aged 14.
- One patient shortly has an appointment with Johnson and Johnson to discuss the possibility of assistance for funding with treatment with Leustatin. Another patient in the group who has completed a course of Leustatin reported that recent CT scans had showed considerable improvement.
- A patient has recently been suffering from fluid retention/kidney problems.
- One patient has been diagnosed with arthritis and is finding coping with the limitations this imposes difficult.
- One member will shortly meet with a couple of doctors on the East Coast: has anyone anything on their mind that they wish the research doctors to know about this disease? One patient mentioned that is it difficult to plan your life without knowing the prognosis for the disease. One member mentioned the importance of research into the disease itself, which hopefully would lead to more effective treatment.
- The next chat will be held on Saturday 10th July 2010 at 3pm EST.