

Summary of ECD Global Alliance chat held on Saturday 17th July 2010

7 Present:

- This week's chat was mainly social, with members exchanging news about what was going on in their lives.
- One member had been interested to hear about a treatment for cancerous tumors which involved high doses of vitamin C given intravenously.
- A friend of a patient has been making a video on ECD featuring the patient and their family. It should be finished soon and it is hoped it will be included in the ECD website.
- A patient described how she had been told in the past that spots (on the skin) were unrelated to ECD. The patient has recently heard of another ECD patient who has very similar spots.
- One patient has recently stopped taking steroids and is feeling better for it.