

## Summary of ECD Global Alliance chat held on Saturday 28th May 2011

5 Present:

- A message was posted prior to the chat from someone who had lost their partner to ECD. The patient had suffered from several of the symptoms discussed in the last chat. They had experienced swelling of the feet and legs as a result of compromised kidney function; dialysis had relieved the symptoms to a degree. Their fingernails and teeth were also affected, with one crumbling molar getting infected. The medication used to treat the infection nearly cost the patient their life and they were hospitalized with nausea and fever. The patient had received social security disability for some years.
- One patient is having difficulties in accessing treatment. Local doctors are reluctant to treat the patient due to lack of knowledge/no experience of ECD and would prefer the patient to contact the doctor who initially diagnosed the condition. It was discussed that there is information available on the ECD Global Alliance website that may be helpful to provide to doctors.
- A patient described how ECD and the side effects of interferon make them feel weak. The patient finds it hard to breathe and their balance is affected. The patient finds that they need to sleep a lot. Treatment with interferon started in November 2005. The patient is no longer able to work.
- The next chat will be held on Saturday 4<sup>th</sup> June 2011 at 3pm EST.