

ECD chat summary

Date: 28th February 2009

8 Present

- Rare Disease Day was held in the US on February 28th. One member had an article published in the local press to mark this.
- Colds – two members reported that their relatives with ECD are badly affected if they catch a cold, and find it takes a long time to get over the cold. These patients have been advised to have antibiotics available to take as soon as they get an infection.
- Two other patients in the group were on antibiotics long term. One patient has been taking antibiotics since August 2007. Another patient has been taking antibiotics since July 2008, when chemotherapy was started. The purpose of this is not to treat the ECD but to reduce the likelihood of other illnesses when the immune system was suppressed. It was agreed to add a note on the website about the use of antibiotics.
- Another website release is in the pipeline, hopefully for Sunday/Monday. It was discussed that it may be helpful to notify members of the group of updates by e-mail, or in the newsletter.
- Raising awareness of ECD was discussed. One member worked at a hospital where morning prayers were devoted to those with rare diseases. Another patient had recently visited an ophthalmologist and encouraged him to present the case to other consultants. It was discussed that as a significant proportion of ECD patients have eye involvement, the ophthalmologists are a good group to target in raising awareness of ECD.
- There was a discussion regarding distribution of information about where members live. This might allow local support groups to be formed. Some thought will be given to how this could be done whilst respecting everyone's privacy.
- Items for the newsletter should be submitted by March 15th to stanceforlance@hotmail.com