

ECD chat summary

Date: 21 February 2009

8 Present

- A fairly new member had been interested in last week's summary re: eye problems, they have had similar problems. Their local doctor is willing to consult Dr Kurzrock in Houston.
- Two members reported some good news. One patient had seen a doctor this week who had said that the ECD was stable, and that the patient did not need to return for another appointment for 9 months. Another patient had a CT scan which showed no changes from January 2008. One patient is experiencing problems finding local doctor to treat them, the group offered to provide any help they possibly could.
- There was a question about whether other patients had suffered from red splotches on the skin. One patient had red splotches on 75% of their body area at one stage, the splotches were neither itchy nor bumpy. They have faded but not disappeared completely. One other patient had had them on and off on the soles of the feet. Another patient also had them on and off and they were very itchy.
- There was a brief discussion about dealing with bone pain, with several patients taking over the counter pain killers
- One patient has been taking part in a sleep study and sleep apnea has been diagnosed. A CPAP mask will be introduced to see if it helps with fatigue, memory loss and high blood pressure.
- The next newsletter is due end March. There was a request for articles (which would need to be submitted by March 15th). If you have any articles, or ideas for articles, for a newsletter, please email them to stanceforlance@hotmail.com.
- The group now numbers 36 plus three other cases represented.
- There was a discussion about Rare Disease Day proclamations. Rare Disease Day is on February 28th. Several patients had received responses to their letters to governors, several had not.