

Summary of ECD Global Alliance chat held on Saturday 2nd January 2010

6 Present

- One patient reported that their chest was much improved following a recent stay in hospital due to problems with their lungs.
- Leg pain is a problem for three patients represented on the chat. One described it as intermittent but it is a constant problem for the other two patients. These two patients take analgesia round the clock to manage the pain.
- It was discussed that when writing a report on a scan, doctors will usually compare the scan just performed to the most recent previous scan.
- A patient in the group had recently received the excellent news that they were in remission and has been off all ECD drugs since August.
- Lung problems were discussed by a couple of patients on the chat. One patient is housebound in cold weather due to problems with their lungs. Another uses bi-pap and oxygen at night, and uses a heated humidifier at home to assist with breathing.
- A patient has contacted two TV shows ('Doctors' and 'Dr. Oz') to try to get some information about ECD presented. One member of the group had submitted their story to the show 'Mystery Diagnosis', as some time ago there had been interest expressed in dedicating an episode of this show to ECD. However, the member has not received a response to date. One member suggested that local news coverage may be achieved if the state you live in declares Rare Disease Day.
- The chat was largely social today and members wished each other a very Happy New Year!