

Summary of ECD Global Alliance chat held on Saturday 24th July 2010

12 Present:

- The NIH (National Institute of Health) is considering the possibility of conducting a study on ECD. An email giving more details about the study was sent on 24 July to all members. It is hoped that everyone will want to participate in the study; it is up to members to make the study a success through their participation. Everyone who is interested in participating should begin gathering their medical records, so that once approval is obtained the study can begin immediately. The NIH will cover the cost of travel, food and lodgings for US participants. It is thought that the study may commence before the end of the year.
- There was a discussion on the subject of patient records and how they may be accessed for research. It is hoped in future that the organization will have a registry where all patient records may be stored and retrieved easily by qualified researchers with the appropriate credentials. However, some work still needs to be done to ensure that everyone's privacy is protected and the the data collected is deemed reliable.
- The question this week was 'How does intense heat and humidity affect your health? Does it cause you more discomfort, pain, other medical problems? Does it force you to stay inside?'
One patient said that increased heat adversely affects their balance. Another patient said the heat made them very tired and humidity made their arthritis worse.
- One patient is having a very difficult time at the moment with dehydration, weight loss and lack of appetite. They have recently had a port a cath inserted and will shortly begin treatment with cladribine. Three other patients on the chat have had treatment with cladribine.
- A question was raised as to whether anyone had a history of seizures. One patient had experienced seizures probably as a result of ECD. One patient had several seizures while growing up, a long time before being diagnosed with ECD.
- Four patients on the chat had diabetes insipidus before receiving a diagnosis of ECD.
- The next chat will be held on Saturday 31 July 2010 at 3pm EST.