

Summary of ECD Global Alliance chat held on Saturday 20th June 2009

11 Present:

- The 'Mystery Diagnosis' program was discussed (a TV company recently contacted the HAA to ask if patients would be prepared to tell their stories in the making of a TV program). One member has sent in details and the producer has acknowledged their correspondence. At least two other members are considering sending in details of their history. For further details, please see the email sent out recently.
- One member is currently experiencing stomach problems (nausea and pain) and they are unsure whether the cause is dietary or due to interferon. One other member also reported problems with nausea which may be due to interferon or due to drinking milk (switching to lactose free milk may help). One member commented that Zofran seems to help some patients with nausea.
- One member has received notification from the Social Sec that they will supply more money for medication. It was suggested that it may be worth applying if patients are struggling financially to pay for medication.
- One patient has recently experienced 6th nerve palsy in one eye, causing pain, closure of the eye (temporarily) and double vision. There is a difference of opinion amongst specialists whether this is due to ECD.
- There was a question from a member who has just started prednisone for pericarditis and is feeling OK so far. When do the side effects i.e. mood swings, weight gain etc (if they occur) start? One patient reported that side effects (choking and difficulty swallowing) started about 3-4 weeks after starting the drug. Another member reported mood swings within a few days of starting the drug. One patient reported bloating and minor mood changes after couple of months. Another person noticed weight gain after a week. One patient said that when being tapered off the drug, the side effects took months to disappear.
- One patient may have difficulty in obtaining interferon where they live, due to financial constraints. In the US, pharmaceutical companies will sometimes help if the out of pocket expenses are too high for the income level. One member suggested the Roche Patient Assistance Foundation. There is a telephone number on the Roche website you can call to see if you qualify for assistance. Another possible website is www.needymeds.com.
- One patient reported less pain, which they thought was due to prednisone.
- Several members discussed the difficulty in finding a local doctor to treat ECD.
- There was a discussion on teeth issues and ECD. There is mention of this in the literature and one member offered to research it with a view to putting some information onto the website. One patient reported 'enamel falling off teeth', another lost teeth as the jaw bone depreciated, one had holes in the teeth and lost a number teeth and one patient had some 'abnormal' gum tissue about 10 years prior to diagnosis.
- A worsening in symptoms (poor balance and onset of nerve palsy) in warm weather was reported by two patients.