

## Summary of ECD Global Alliance chat held on Saturday 1<sup>st</sup> January 2011

### 7 Present

- It was with great sadness that the group learnt of the death of Jim Carmon, aged 79. Jim died on December 20<sup>th</sup>, surrounded by his family. Jim was a regular chatter and will be much missed.
- A question from a patient was posted at the beginning of the chat, 'Are there any ECD sufferers who have trouble with cold fingers?' Please post any responses to this question on the chat room, which may be accessed at any time.
- One patient is in hospital receiving treatment for a new ECD lesion on the brain stem. A week before Christmas they woke with eyes looking to the left and loss of sensation in the face. They are being treated with high dose methotrexate (so far 1400mg intravenously over 6 hours followed by folinic acid for four days). This treatment was selected as it crosses the blood brain barrier. The patient is responding to treatment and has regained some feeling in the face. The patient has suffered relatively few side effects although there has been an increase in fatigue and a mild reaction in the vocal chords thought to be due to dexamethadone, a cortisone based drug used in association with high dose methotrexate.
- Another patient on the chat had been taking methotrexate for about a year, at a dose of 40mg a week. It is thought that the treatment is having a beneficial effect and they have no side effects.
- It was discussed that it is thought that ECD can adversely affect the teeth and jaw bone. There are some reports in the literature of crumbling/breaking teeth and one patient represented on the chat has experienced this problem.
- Members were asked how they were getting on in preparing medical records to send for Dr. Vaglio's study. Are there any issues surrounding this?
- Nine patient have registered with the ECD Global Alliance in the last two months.
- It was discussed that it is common for carers to feel deflated and exhausted following a dramatic change/worsening in condition of their loved one.
- One patient reported that rain/change in pressure had caused their leg to swell and caused some pain. It was agreed that changes in the weather can cause problems for ECD patients.
- Members wished each other a Happy New Year.
- The next chat will be held on Saturday 8<sup>th</sup> January 2011 at 3pm EST.