

## **Summary of ECD Global Alliance chat held on Saturday 29th January 2011**

7 Present

- A patient who was recently in hospital receiving treatment with high dose methotrexate for a brain lesion is now home. Initial indications of the effect of the treatment are positive.
- One patient reported that they have now been in remission for one year and one month.
- A patient who has been taking methotrexate for the last 15-16 months received the results from a recent PET CT scan. The results were good; the scan indicated no active disease at present.
- Two patients have been suffering badly with coughs recently.
- A question was asked about weakened immune systems and ECD. It was commented that the medicines used to treat ECD can adversely affect the immune system.
- Members were encouraged to wear their ECD Global Alliance t-shirts to mark Rare Disease Day on February 28<sup>th</sup>.
- The next chat will be held on Saturday 5<sup>th</sup> February 2011 at 3pm EST.