

## Summary of ECD Global Alliance chat held on Saturday 16th January 2010

8 Present

- Members were reminded to write to their state governor asking them to adopt February 28<sup>th</sup> as Rare Disease Day.
- A patient who has taken a course of 2CdA commented that this chemotherapy seems to have slowed, but not stopped, the progress of the disease. The patient felt tired whilst taking 2CdA but otherwise experienced few side effects from the chemotherapy.
- A patient taking Kineret, in the form of a subcutaneous injection once daily, has found that this has reduced their bone and joint pain to almost nothing. The only side effect has been some irritation at the injection site, but this has been minimal.
- One patient taking interferon has recently attended the eye hospital and reported that their orbital masses appeared to be exactly the same as they were a year ago.
- It was discussed that quite a few ECD patients suffer from diabetes insipidus.
- Several patients commented that, when they look back to the time before they were diagnosed, they can identify symptoms that may have been due to ECD.
- The newsletter editor was pleased to have been sent so many pictures for the newsletter but would like some more! Please email your pictures to 'stanceforlance@hotmail.com'.