

## Summary of ECD Global Alliance chat held on Saturday 12<sup>th</sup> March 2011

9 Present:

- One patient who has just completed their 3<sup>rd</sup> cycle of 2cda is feeling better than they have for months. They have not experienced side effects with the treatment (apart from vivid dreams!). This patient was diagnosed in December 2009 and has brain stem involvement which affects their left side and they have problems with their balance. The patient is due to have an MRI scan shortly, which will be the first since treatment commenced.
- One patient is still having problems with choking a lot.
- Several members had listened to the interview with two Canadian patients on CBC, which was very good. A link to the interview can be found here - <http://www.cbc.ca/thecurrent/episode/2011/03/11/rare-diseases/#>.
- A patient receiving treatment with high dose methotrexate for a brain lesion is doing well. The patient is due to be admitted to hospital again this week for the fifth treatment.
- There was a discussion about patients having problems with loss of strength and co-ordination and shaking in their hands. Several patients represented on the chat have this problem and mentioned that it makes eating difficult.
- One patient is recovering well from eye surgery which took place this week.
- Daylight saving starts in the US this weekend. Non US members should be aware of this to avoid logging on early or late for the weekly chat!
- The next chat will be held on Saturday 19<sup>th</sup> March at 3pm EST.