

Summary of ECD Global Alliance chat held on Saturday 4th April 2009

8 Present

- This Saturday's session marked the first anniversary of the first ECD chat session. Members were invited to post in the chat room what the group had meant to them. Several members did this and described how much the group had meant in terms of support and encouragement and in gaining insight into the disease. The group started with six members and now has forty.
- It was suggested (and agreed) that the time for the next ECD chat should be mentioned in the current chat. The time is usually Saturdays 3pm (EST).
- Several very positive comments were made about the recent newsletter which was sent out and will be posted on the website.
- One member asked whether anybody had any experience of cladribine, which was being suggested as a possible future treatment. The experience of one member was that it made them feel sick and tired. (Summarizers note: Simon was on cladribine for 6 months and had a good experience, no nausea nor tiredness and no other side effects. He was on the subcutaneous form of the drug, not IV).
- Several members had participated in a telephone call with Dr. V in Italy, who is considering doing research into ECD. If he obtains approval for the research he will need copies of patient records of as many ECD patients as possible. Dr. V explained that it was only by looking at details of lots of cases that he may be able to improve the ease of diagnosis. It was suggested that everyone in the group give some thought to how copies of patient records could be obtained for Dr. V. if the research goes ahead.
- A question re: calcium supplements was raised in a chat a few weeks ago. A nephrologist has stated that there are no concerns with taking calcium supplements. As always, make sure your doctor knows about everything (EVERYTHING) you take – side-effects can be unexpected and nasty.
- There was some discussion regarding ECD treatments at the large institutions. It is not always clear how many patients are being treated and how many doctors might be involved in treating the cases. It is often times helpful and enlightening when patients (or loves ones) discuss with their doctor(s) the numbers of cases being treated at the institution.