

## Summary of ECD Global Alliance chat held on Saturday 16th May 2009

10 Present:

- Several new members were welcomed to the chat and shared their experiences.
- At least three people on the chat today had received a diagnosis (or relatives had received a diagnosis) within the last 6 months.
- A question was raised. 'Has anyone had a problem getting temporary Disability while receiving treatment?' At least one member receives disability, although it took a couple of tries. Another patient is going through the process currently and finding it frustrating. Some have suggested a lawyer may help.
- One member had just completed the first cycle (5 days) of cladribine and reported that, except for tiredness, there were no other problems. One other person on the chat reported that their relative was taking cladribine.
- Members discussed their experiences with prednisone. One member said that it did a lot of good, but that there were also adverse effects. One other member in the chat was still taking prednisone and one other had taken it. It was thought that prednisone can be effective but that you need to be aware of the possible side effects.
- Some members reported pre-existing heart conditions prior to diagnosis with ECD.
- One member asked whether anyone else has broken a bone with ECD. One other member reported that they had.
- There was a discussion regarding life expectancy and ECD. There are members of the group who have lived much longer than some of the statistics that you read about on the internet. The case log on the ECD website (Patient-to Patient section) details some of the long lengths of time that some people have been living with a diagnosis of ECD.
- Loss of appetite was discussed. One member thought that the longer they were on interferon, the worse things tasted. Other members reported loss of appetite and that everything tasted bad. Several people mentioned a metallic taste in the mouth and it was suggested that this may be worth raising with the doctors with some experience of ECD.
- Several members mentioned the experience of lightheadedness and the feeling that they may pass out. One person mentioned that they felt pressure in the head.
- One member raised a question about whether anyone else had experienced swelling or pressure in the back. One other person reported lower back pain.