

## Summary of ECD Global Alliance chat held on Saturday 8th May 2010

9 Present

- One patient who has recently had cataract surgery on their left eye has noticed that the pain behind the left eye is significantly decreased. It is thought that the cataracts are as a result of being on prednisolone long term, rather than being related to ECD.
- A patient who has recently had a course of cladribine is having scans this week to assess the effect of the medication.
- It was noted that there are many on the chat that have been making good progress with their treatments; this is very encouraging for the rest of the group.
- A caregiver commented that their relative with ECD found it difficult to fight off any illness and when they were sick they were very sick. Several patients on the chat said this was also true for them, although this may be related to the medication the patient is taking e.g. chemotherapy rather than ECD.
- One patient will shortly start treatment with Enbrel/etanercept, an anti tumour necrosis factor drug (related to Kineret). The doctor has told the patient that they will be very susceptible to infection on this drug.
- The issue of trying to aid communication between doctors treating ECD patients was discussed, with one member suggesting that they might form their own chat room in order to discuss what they are doing for their patients. It was also suggested that patients use the chat room to share with each other what their doctors have said about their condition/treatments. One member forwards the summary of the chats to their doctor.
- One member asked whether anyone took supplements. One patient is taking supplements prescribed by a homeopathic doctor (including vitamin D), one patient takes vitamin C and D supplements; one patient takes B, D and E supplements.
- Several patients described how they suffer with leg pain. One patient has had nine surgeries in both legs, with little improvement. Extreme osteoporosis has made the bones very brittle and the patient often has hairline fractures. The patient has had bone grafts in both legs in an attempt to strengthen them. Several patients on the chat have very limited mobility due to problems with their legs.
- The question for discussion this week was “What are the things you enjoy about the chat room? What do you get from talking to others who have the same or similar problems? As a caregiver, how does the chat help you?” Some responses were as follows.
  - The chat is the only chance I have of having contact with other ECD sufferers.
  - Even if we are all a bit different, we can often help out with ideas and ways of doing things.
  - The chat is my lifeline, I will do anything so I can join the chat.
  - It is nice to have contact with others who have the same problems.
  - It is helpful to hear about others good results.
  - It is valuable to hear about what others are going through, the types of treatments that have helped and those that have not.

- A caregiver said it was their job to find out as much information as possible, and the chats were a source of information.
- The next chat will be held on Saturday 15<sup>th</sup> May, 3pm EST.