

Summary of ECD Global Alliance Internet Chat

28 April 2012

9 Attendees

- Before the Chat started a new person/member logged on saying that they were a student writing a research paper on ECD and was interested in interviewing someone with ECD. Kathy has contacted this person to learn more about the request, but has not heard back.
- A member said that it was unbelievable how changeable an ECD patient is from day to day. Interferon is causing many side effects although it is only used three times a week. On a good day, which isn't often, it is possible to go fishing.
- One of the founding members of the Alliance and initiator of the Chats came on. It had been a long time since she chatted. Her husband is pretty stable now. No hospital admissions since last summer, and the semester, for her, has ended so, as Alice C sang, "School's Out For Summer"!! Her husband is being treated with Actemra (a drug that is used in Rheumatoid arthritis). This has made a great improvement. Infusions are given every 4 weeks at present, but this may be extended to 6 weeks, since he is doing so well. Initially it was at a dose of 8 units per infusion. This was dropped to 4 because of side-effects (a low blood pressure, and a low white cell count). It started to improve things after the second or third infusion. Bone and joint pain has gone away, but it does cause fatigue, even at the lower dose.
- Another member has just started Actemra at monthly intervals; only 2 infusions so far. No improvement yet, just side-effects (mouth ulcers, hair loss, and low blood pressure)!
- The member, whose partner recently died from the effects of ECD, came on. There is, now, lots of time in the day, to get things done. It is possible to do more walking, and even "go to the gym".
- It was generally agreed that prolonged and frequent hospitalizations are difficult to cope with, and patients much prefer to be at home, even when they are very unwell.
- A member who has had prolonged back pain is not doing too badly now.
- An enquiry was made about the situation regarding whether Histiocytosis is now on the List of Diseases that the Social Security uses. A member has previously been denied twice, and refused leave to appeal.
- Many members joined in a discussion over diet. It was said, frequently, that eating a "healthy" diet, with much less junk food, and more fresh stuff, made members feel better. Chocolate was one exception. Although a "junk food", it was generally considered an essential part of any diet. A member, who is a "mild" diabetic, is trying to alter diet with the help of a dietitian. Physical exercise, when possible, was recommended too.
- A member wanted to know the name of the new member from Phoenix. This was given.