

Summary of ECD Global Alliance chat held on Saturday 12th December 2009

12 Present

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- One patient has recently had a biopsy of their knee, and has been prescribed Gleevec. They are due to see their specialist again this week for further discussions on the course of treatment suggested.
- A patient has recently started to use a talking computer.
- An ECD patient will be the subject of a paper by Dr. Stacy Pineles that will be presented in Arizona in March.
- A question was raised as to whether anyone was having problems with their interferon supply. A patient has been told that the pens had been recalled and that they may not be back on the market. No-one on the chat had experienced any problems with supplies of interferon.
- There was a brief discussion on the topic of leg cramps. Two patients have taken quinine to help ease the cramps. One patient ensures that magnesium levels are up and also finds that a shiatsu massager helps.
- One ECD patient described the difficulties in having ECD and having to be a caregiver for their seriously ill partner. Messages of support and encouragement were offered; one of the main purposes of the chats is to help and support each other.
- A number of patients participating in the chat, or represented on the chat, take prednisolone. Two patients reported that they had been taking it for 10 years and thought that their quality of life would be much worse without it. Different dose regimens were discussed. One patient had had the very high dose of 80mg a day for months, in an attempt to treat tumors in the eye orbits. Side effects were weight gain and muscle weakness. One patient takes 10 mg a day without side effects. Another patient normally takes 10mg a day, although when planning to be more active, increases the dosage two days before and then a couple of days after. They also reported no side effects. Another patient takes prednisolone for one week and then has three weeks off, and felt much better when taking the drug.
- Everyone on the chat wished each other a very Happy Christmas!