

Summary of ECD Global Alliance chat held on Saturday 4th December 2010

6 Present

- A question was posed by a patient prior to the chat as to whether other patients experienced tremors in their hands/arms when trying to do things e.g. eating, lifting. No-one on the chat had experience of this.
- One patient is doing very well at present and is able to walk most days and do pilates on a regular basis.
- A new member was welcomed to the chat. Their spouse has just been diagnosed with ECD and has been in hospital for the past two weeks.. They have started treatment with prednisolone and interferon this week. The patient had been seeing specialists for eleven months before diagnosis. Initial signs and symptoms included a bad cough, weakness in the legs, feeling lethargic and very tired, night sweats and weight loss of 40 pounds. One of the main areas affected is the lungs.
- One member commented that the time just after diagnosis was a difficult time but that they had felt some relief at this point that the disease had a name and that treatments could be slightly more focused than by means of 'guesswork'.
- It was discussed that response to treatments was highly variable and individual. For example, for some patients, treatment with prednisolone results in a huge improvement, whereas for some it has no affect at all. Outcomes for ECD patients are highly variable.
- The ages for the ECD patients on the chat (or represented on the chat) today were 59, 62, 55 and 49.
- Most patients on the chat had undergone at least one biopsy prior to diagnosis.
- It was discussed that it was very unusual for ECD to 'disappear'. More often is it a matter of trying to find a treatment to bring the disease under control and then adapting your lifestyle according to the nature of the disease.
- It was discussed that ECD can deposit in most places in the body.
- A question was asked about how long (if at all) patients had been hospitalized. One patient had only been hospitalized for a couple of days (for a biopsy) and another had been in hospital for two and a half weeks.
- The next chat will take place on Saturday 11th December 2010 at 3pm EST.