

ECD Global Alliance Internet Chat 03 Mar 2012

9 Attendees

- A 44 year old patient with ECD has symptoms of balance, speech problems and constant shaking. It was asked whether any member of the group had these symptoms subside once they had started treatment. The patient has just been put on Interferon injections, after being on several other medications.

Another member posted that a soon to be 47 year old patient does not have the shaking, but has had, and still has, horrible balance and slurred speech when he is tired. With treatment (Gleevec) he has just been informed that the time between visits to see Dr. Kurzrock has been extended from 3 months to every 6 months. This is wonderful as it indicates all is going well for the patient.

- A long-time member from Australia provided an update on his wife's condition. The ECD is progressing slowly, taking away functionality as the days pass, but they remain happy, without infections, and are laughing together. The timing of the Chat doesn't work for him to attend (it is very early in the morning in Australia!).
- One member has just had a physiotherapy evaluation, to see how his back pain may be lessened. He is going to go twice a week for some "more challenging" sessions! He uses ibuprofen, a heating pad, and Aspircreme to try to get some relief.
- Another member who has been having injection treatment for back pain is still having some pain, but is able to move a bit.
- One member's records have been sent off to NIH. They weighed 10 lbs!! It took months to get records from the doctor to send.
- A member who has already been to NIH said that his oncologist was "surprised" to find that there was a 50 page report!
- Another member told us that the doctor at the NIH didn't get the medical records from Norway, until the day after the visit to the NIH had finished!

- A member asked about the data that the NIH wants, and was advised to send as much medical information as possible, especially from the time after diagnosis. He was also advised to contact Kathy (support@erdheim-chester.org) to get an appointment at the NIH arranged, and was reminded that THEY pick up the tab for all the tests, travel, and accommodation, and provide a full report. However they don't get involved with the treatment side of things. Members were encouraged to take part in the NIH study, if at all possible.
- A fairly new member, whose husband has ECD said that she was trying to talk him into going to the NIH. The patient's back has been hurting, affecting his sleep. This is due to the ECD in his kidneys and adrenal glands. A biopsy of his kidney and adrenals was performed, and the doctor said it was as hard as the table! They tried a needle biopsy but the needles wouldn't penetrate. A month later they did an open biopsy.
- The son of another member had had an attempted exploratory operation, but the doctors "could not get in".
- Two members discussed the wonderful effect of the arrival of spring on women's clothing!