

Summary of ECD Global Alliance Internet Chat 06 April 2013

5 Attendees

- For the first 15 minutes, there were only 2 Chatters. They exchanged the usual greetings, queries about how each was doing, and what the weather was like. One of these Chatters then went for an early night, but others then came along.
- A member has just got physiotherapy arranged. It will be 3 times a week, and, the member believes that, it is probably going to be quite intense. The member can walk on a flat surface, but not hills, and the therapist thinks that the problem might be tendonitis. Another member is also starting some intensive physiotherapy next week. This will be everyday, for 1.5 hours, for 3 weeks.
- Then members discussed a "new" treatment, LDN (Low Dose Naltrexone).

Summariser's note (a retired doctor writes): Naltrexone is a drug that blocks the opiate receptors in the central nervous system. The CNS produces opiate-like compounds, itself, called endorphins. The opiate receptors respond to these. Naltrexone is used in patients who are trying to get off opiate drugs (heroin mainly), because it blocks the "effect" of the heroin, so that there is no point in taking it. Recently, it has been tried in all sorts of conditions, and some patients have reported that it has been helpful. No trials have been done, and there isn't any obvious reason why this drug should help in these conditions.

One member has persuaded the neurologist, involved in her case, to give a prescription for naltrexone, although it has not been started yet.

- The BRAF inhibitor trial, that is ongoing, was mentioned. More information can be found at <http://www.erdheim-chester.org/ECDStudies.html>
- Members were reminded that there is quite a few other treatment options if interferon is not helping. These include, but are not limited to, Gleevec, anakinra, BRAF-inhibitor, methotrexate, and 2CDA.
- A member is, shortly, going to a haematologist for consideration of a course of cladribine (2CDA).
- The ECD Global Alliance wishes to put out a newsletter soon. Members were asked whether there was anything, particular, that they would like to see in it.
- Members were asked whether they would like a rehab specialist to join the chat session one day, to talk about physical therapy options, and ways to improve the quality of life. This might be possible. Dr. Estrada-Veras is looking into this for us!!! We were asked to start thinking of what we might want to ask a rehab specialist, if one was available on the chat. If it should happen, it would be great if we could keep them busy answering questions for the entire hour!!
- A member, who has been to the NIH has been trying to track down a biopsy tissue taken from the orbit previously at another institution. The search has been unsuccessful.