

Summary of ECD Global Alliance Internet Chat 17 Nov 2012

7 Attendees

- Before the Chat started, someone posted that they were writing a report about ECD, and asked whether anyone has any important information to share. A request for details about the "report" was made, giving the support@erdheim-chester.org e-mail address and stating that "We would be happy to help you."
- A member is going back to the NIH next week, 1 year after the first visit. Another member, who went to Bethesda last year, may be going for a second time in the next year. The member, who is making a return trip to NIH, has received her schedule. There are no appointments after 3 pm, but her days start early. She expects to be able to get some shopping done!
- A member came on, who had a very busy schedule. Fighting a cold, trying to get some sleep, performing in "Scrooge, The Musical", and coming on the Chat!
- Other members discussed sleeping problems. The commonest problem was falling asleep too easily, and sleeping for a long time (12hours+ in one case). A member said that excessive sleepiness had occurred while on interferon, but had not been such a problem since swapping to kineret.
- A member had had some problems with a pharmacy this week. The wrong strength of fentanyl patch had been issued. Also he finds that his legs feel weak, although he isn't having much pain.
- A new Chatter came on, from Phoenix, Arizona. He has ECD, himself, is aged 47, and was diagnosed in 2009. The other chatters gave brief details of year of diagnosis and of treatments that they had used so far. The new chatter is currently receiving treatment for ECD, but he doesn't feel that it is helping. He wasn't able to tell us which treatments he was using. He has a doctor's appointment on the 27 Dec. He was advised to discuss matters with the doctor if he feels that the treatments are not working, and to let his doctor know, that there are research doctors who are willing to consult with him/her. They can let his doctor know about other treatment options. Requests for contact information for these ECD-knowledgeable doctors can be obtained by emailing a request to support@erdheim-chester.org.
- The Houston meeting held in Houston on Nov 12-13 went very well. ECD Global Alliance Board members got to meet each other "in the flesh" for the first time. An organizational plan for 2013 was drafted. On the second day, a group of 8 doctors/researchers reported on their findings to date. The doctors shared information, and began discussions about possible collaborations. This was all very hopeful. It was uplifting to listen to researchers who really do want to find answers to all the ECD questions we have.

- Dr Estrada Veras attended the ECD Houston meeting. He has new patients scheduled, as well as follow-ups. He said that, by the end the year they will have seen 20 ECD patients.
- Next year, in late October, there will be a similar meeting in San Diego to which all ECD patients will be invited. The dates and location will, hopefully, be firmed up within the next month. Most likely the 2013 meeting will be the very end of October in San Diego. "Hold the date!"
- During the Houston meeting, it was discussed that when patients join together, it makes research easier to do. When patients register with the organization, it shows there is a group of patients that can be easily reached for research purposes.