

ECD Global Alliance Chat Summary

5th November 2011

8 Attendees

- A member, who has been having a lot of back pain, is scheduled for an injection into his back next week. The doctor thinks that he may need surgery (pins and plates) in the future. He is going to be seen again in 6 weeks, to see if the injection has been effective.
- A number of members have been able to meet up during all the comings and goings to the NIH at Bethesda. These meetings have all gone well so far, and have been enjoyed by the participants.
- In the UK, it was Guy Fawkes Night; lots of bonfires and fireworks, commemorating the foiling of “The Gunpowder Plot” to blow up the Houses of Parliament in London.
- A member said that all was ready for the trip to Bethesda next week, and arrangements were in place to meet friends that live nearby. Another member has a tentative date for NIH.
- So far, all reports about the team at NIH are very positive. The NIH is very interested in a possible genetic link in ECD, and is willing to take blood from other family members if they come with you. Otherwise, they can let you know how to get other people’s blood samples collected, to be part of the study
- We know that our member from Europe who was flying over to NIH, arrived safely in MD.
- Another member was e-mailed by NIH this week. They will ring next week to sort out dates.
- One member had been called by the doctor this week, because there had been a “spike” in the blood cholesterol level. This had not been an issue before. Possibly this might be due to the kineret treatment. The member exercises, and has a good diet. The plan is to check it again in the future, but not to start treatment at present.
- One member’s 15 year old grand-daughter had shot a 4 point deer that morning. This was her second.
- Two members have an interest in wood-turning, and enjoy lathe work.
- There was a discussion about a particular form of thyroid disease (Hashimoto’s thyroiditis). One of the Chatters suffers from this although they are not the person with ECD, and one member who has got ECD, had it diagnosed a long time before the ECD.
- A member asked whether anyone else was troubled by claustrophobia (a fear of being in enclosed spaces, like elevators).
- It was generally agreed that it would be great if we could all meet up someday. It is one of the dreams of the organization. We'd like to get the researchers together for a day or two, followed by all of us. Then one or two of the researchers could stay over with the patients/families to interpret what the researchers had to say.