

## Summary Of ECD Global Alliance Internet Chat 20<sup>th</sup> October 2012

5 Attendees

- A member has been having leg pain, and is finding that ibuprofen is not strong enough to help. Other members were asked whether they also suffered from pain. One member said that pain was only a problem after falling over, or banging into solid objects!
- A new Chatter came on, whose brother-in-law had ECD diagnosed a month ago. He is a rep for a company making medicines! He is 50 years old, and has 2 children, both under 10 years of age. He was sick for a year before diagnosis, and is currently hospitalized, with ascites (fluid in the abdominal cavity) and kidneys only functioning at 20%. About 5 weeks ago, he started having trouble breathing, and poor kidney function. His heart wasn't working as it should, and he started to get ascites. He was transferred to Mayo and they diagnosed ECD after 3 days. He is now receiving interferon, has his ascites drained twice a week, and is on kidney dialysis, (and also a low potassium, and low phosphorus diet). Keeping food down is difficult, and a feeding tube has been suggested.
- Members were asked about their symptoms, their treatment, and where they lived. One member used to fall about, had slurred speech, and double vision. The ECD was in the brain, lungs, around the heart, and behind the eyes. Treatment is currently weekly low dose methotrexate (forty milligrams).
- Another member had had 2CDA treatment, but was not on anything at present. Another has been on interferon for a year. The MRI scan shows no active lesions, and the interferon dose is now low. Bad balance, and leg stiffness were the main problems for one member. Another member complained of a lot of leg and back pain, and another had had to take medical retirement aged 45.
- The Chatters came from Norway, UK, Georgia US, and Pennsylvania US, and the new Chatter from Rochester, NY.
- The NIH study at Bethesda was mentioned. There is a team of doctors there, which is interested in the disease. The first time you go it is testing from A to Z, and speaking with the doctors. One member is about to go for a second visit, and it was recommended as a trip for the brother-in-law of the new member, when he is feeling up to it