

Summary of ECD Global Alliance Chat on 2011-08-20

9 Present

- One member said that he was in contact with the NIH and is waiting for his records to be sent there. Another member said that he was planning to go to the NIH. One member has had a busy week trying to get the necessary records together to send them to NIH.
- A number of members are in the process of getting their records together for the various projects on ECD that are starting. One is soon going to be booking a place at the NIH for "the week". It will be very interesting for us to know how it all works out.
- One member has been having a bad time due to back problems and is waiting to see a spine specialist. The therapist that the patient is seeing at the moment is doing some good. What the patient thought was pain from his hip is actually from the sciatic nerve and back disease.
- A member mentioned weight gain of 20lbs in 18 days! Fluid retention was suggested as a possible cause. The patient was put onto prednisone because of side effects from Kineret and has been taking Lasix (furosemide, frusemide in the UK) by mouth. The patient plans to ask to receive it intravenously as this may be more effective.
- Another member said that prednisone (known as prednisolone in the UK) had caused him to have fatigue, depression, and insomnia. He also had a hip replacement some years later. He thinks that he needed this because of the steroid use, which had affected the hip joint. It was a "standard" hip replacement and did not need to be different because he had ECD.
- It was stated that some people have found that the continued use of a smallish dose of steroids, does help to keep the disease under control, but others find that the side effects are too unpleasant to carry on with it.
- One member was reported as having been treated with interferon, but only for 7 days. A review of his case and treatment is ongoing. Another member said that it took 6 months of interferon before an effect was seen in his case.
- A member reported that he had spent many years on various treatments with no success, then interferon was tried and this worked quickly. He did suffer the "flu-like" symptoms that are often described. He is now taking kineret and not interferon.
- Some of the various ECD treatments being used seem to be 2cda (aka Cladribine), interferon, methotrexate, Kineret, Gleevec, actemra, sirolimus, tamoxifen, etc. Other known treatments being used and can be found on the www.erdheim-chester.org website.
- Some members have met up for a social visit and everyone involved enjoyed themselves.

- One member is doing much better, and was making peanut butter and jam sandwiches ready for a trip out!
- It was mentioned that getting images of scans and x-rays on CD makes them much easier to send to different research teams. The Global Alliance can advise on ways to get these CDs.
- Dental problems were discussed. Some members have had considerable problems, with teeth crumbling away! It was said that the NIH study will include a dental evaluation.
- Chatters were told about a member who is entering the "Ironman" competition in British Columbia, Canada on 28th August. This involves a 2.4 mile swim, 112 mile bike ride, and then a marathon to run! He is going to be bib 970.
- Another member is starting a blog on Facebook called "Defying a Frightening Diagnosis". The FaceBook link is: <http://www.facebook.com/groups/241550579217632/>.
- An enquiry was made as to whether any ECD sufferers have twitches in their hands.