

ECD Global Alliance Internet Chat 31 Mar 2012 Summary

10 Attendees

- Before the Chat started three people logged in. Firstly, a woman enquired about treatments. Her mother had been given the diagnosis that morning, after some weeks in hospital. Another person said that she had the same questions.
- A member, whose wife has just died from the effects of ECD, came on and reported some of the details. His wife had had a 16 month deterioration in her condition, with a number of episodes of severe illness. He told us that she had died peacefully, and did not appear to be in any pain or discomfort. He requested that donations to ECDGA should be made in lieu of flowers. He thanked us for the love and support given over the last few years. Members offered their condolences.
- A member (non-ECD patient) had just had hernia surgery, and this was causing some pain. A trade of the “hernia pain” for ECD was declined.
- Alpha- interferon has been recommended as a treatment by a member’s doctor, but the patient is concerned about the possible side-effects. The patient felt he had not had a long enough time on steroids, to see if they were working. He would prefer to be given the pegylated form of alpha-interferon.
- One member had had very little in the way of side-effects from interferon, but it hadn’t worked on the ECD! Most other members, who had been on it, had found that they felt pretty rough! Sometimes the side-effects eased up with time. One member has been on interferon for 7 years, and still continually feels exhausted, but his ECD has been under control. He had asked his doctor about the length of planned treatment. “Until it stops working” was the answer!
- A member, whose vision has been severely damaged due to ECD, had had to see a Social Security doctor to assess her vision and decide whether she was still in need of assistance. Her own doctor’s results had been sent, but they were not accepted. She was tested and told that she still qualified for benefits. Her family thinks that the SS staff are told of the diagnosis of ECD. They have never heard of this, so they call people in to see what is going on. She is receiving benefits because of her blindness and NOT because of the ECD. ECD is not on the list of Social Security Conditions. The Alliance is trying to have ECD listed on the Compassionate Allowances list, but it may well take a long time.
- One of our members affected by back pain, had felt somewhat better, until a couple of days ago. She is still attending physiotherapy, and wonders whether she sometimes tries to do too much. Her recent annual visit, to her regular doctor, resulted in a lot of tests being done. The results are, hopefully, going to be good.
- Another member who also has been having physiotherapy, enjoys it, but finds it rather tiring!
- Another member is feeling good after her recent round of treatment. She has family staying with her, and she spent last week at the beach. “Life is good!”
- The 5K run/walk fundraiser held in Louisiana went well. There was a good turn-out, a fair amount of \$ was raised, as was awareness of the condition.
- A member was on a recent run/walk in her rural hometown and she met a woman wearing a Histiocytosis Association of America shirt. This woman has a friend with a son affected. An attempt is being made by our member to connect with the affected family.

- We were told that the woman who has been making a film on histiocytosis has completed her work, and is just waiting for some “releases” and legal d documentation. The website for the film is www.histiowarriors.mixform.com. Information about the film or any updates will be posted there.
- Recommendations for particularly helpful exercise regimes were sought. Swimming has been found helpful (and it doesn't matter if you fall over!). Using a stationary bike was mentioned. Physiotherapy was recommended for improving balance, as were trampoline exercises, and leg and back stretches.
- Orientation and Mobility Training has started for one of our members. This is used by blind people, and is being provided by the Blind Association.
- One member had heard from Sandy in Canada this week. Please drop her a line if you have her email, even just to say “Hi”.