

ECD Global Alliance Internet Chat Summary for 19 Nov 2011

9 Attendees

- Before the Chat started there had already been some "activity". A new Chatter started things off, seeking more information about ECD, and another member started a conversation with her, describing the effects of ECD on the person with ECD and their family. The regular Chatter said that the ECD had affected the kidneys and lower legs. The speech is slurred, and balance bad. It took 10 years to get a diagnosis. There was diabetes insipidus (an inability to make concentrated urine) from birth, and the family believe that this was the start of the ECD. There were also problems with both knees.

This member has been one of the first to go to NIH. The tests showed an improvement in the adrenal glands. 50 pages of results were given after the stay! The NIH staff were "wonderful".

Back pain is beginning to be a problem. Blood sugars are fine. Gleevec is the current treatment.

- The new Chatter's spouse was diagnosed a year ago, with kidney, adrenal, and leg involvement. There have been problems due to low blood sugars, also a lot of back pain.
- Once the "proper" Chat had started, the "old-timer" (sorry Hugs if that isn't a good description. Please don't hit me too hard!!), said that the person with ECD, had not had a good week, and was not able to get into work.
- A member does some work as a foster-parent, although has none in their care at the moment.
- A member had just completed a week at NIH. It had been an interesting and "enjoyable" stay. Getting involved in the NIH study was thoroughly recommended. The brain MRI had shown that the ECD tissue behind the eyes had retracted significantly since ECD was diagnosed 10 years ago. The member thinks that the improvement is due to the interferon treatment.
- The NIH had given a "pass out" on one night, and transport both ways to a friends house for dinner! Suggestions had been given by NIH staff as to

changes in diet. Chicken and fish were recommended rather than red meat, and processed foods were to be avoided. At the start of the illness there had been a significant weight loss, but since starting kineret, the weight has returned (and some!). Return of appetite is thought to be the reason. The tests had shown that the blood potassium and cholesterol levels were raised, and the blood pressure was up. 44 pages of results were handed over, and the conclusion was that the patient was healthy apart from having ECD!

Incidental gallstones were found, and a nodule in the thyroid gland. This was not thought to be significant, but it was recommended to get it checked out.

- Another member who had just been to NIH (having travelled all the way from Europe) is tired, but improving with extra rest. It was suggested that the interferon treatment might be the cause of the tiredness, since fatigue is a common side-effect.
- A member who will be going to NIH shortly, wonders whether his eye disease has retracted too. His sight has improved in recent times.
- The NIH team are looking at various factors (genetic, diet, environment) which might be involved in ECD.
- Another member is still waiting for a date to be agreed on.
- A member, who has been having trouble with back pain, is slowly improving, and continuing with PT twice a week. Stress has caused weight loss, and the member is trying to gain weight.
- Another, who also gets back pain, has a stationary exercise bike, at home, that he uses after work. When the legs won't "work" properly then rest is the only option. The legs get "paralysed" and won't work properly.
- Some members are finding the timing of the Chat to be a problem. Some different times will be tried out. NOT instead of the Saturday Chat, but AS WELL!.
- The staff at the NIH had commented that they were pleased that the Chatline was helping to increase all of our knowledge of ECD. Members who have been to the NIH may be asked back in the future. Two of those that have been already, immediately said that they would go again.