

## Summary of ECD Global Alliance Internet Chat

### 07 July 2012

#### 11 Attendees

- Before the Chat “proper” started a member came on , whose step-father had died of ECD in 2006, and asked whether a cure was nearer, and whether any research was being done.
- A member came on, who had been unable to Chat for a couple of weeks. The interferon dose had been doubled and the member “hadn’t felt too good”. Other members sympathised with this. Most had had trouble with side-effects. Some members continue with side-effects despite having been on treatment for years. One member had bad effects for a year. [Our summary author says, “One member had no side-effects at all! They were probably fake shots, just water, and the pharmacist got to keep all the cash! ☺”] Interferon seems to have good effects for some members, but no effect on the ECD in others. Some members are on a type of interferon that requires only once weekly interferon shots, while others are on a type of interferon with a 3 time a week schedule.
- One member is taking once weekly shots of interferon, which seem to be helping, particularly with brain and bone marrow lesions (the granulomata are shrinking, no progression).
- A member asked how others manage to get “motivated”. This member has lymph nodes that are very swollen, and sores all over. After a lifetime of “good health”, ECD has been difficult to accept. The diagnosis was only made in April.
- Members told each other where in the States they live.
- Some members were generally sleepy, while one had difficulty getting to sleep on some nights, and no trouble at all on others.
- The merits of air-conditioning were discussed. Everyone was in favour.
- Weight was discussed. One member cannot put weight on. Another member lost 35lbs while on interferon, and put it all back on when the interferon was swapped for kineret!! Another member can’t lose an ounce. In this case, living with a wonderful cook is the problem.
- A number of members described arm pains. Often in the elbow, and radiating down to the hand, but up to the shoulder in another member. Neurontin 800mg 3 times a day has helped one member a bit, and there have been no side-effects. Neurontin is used for nerve pain. In one member, EMG (nerve) studies showed that the nerves were OK, and it was all put down to nerve pain. A member had been given neurontin as a treatment for the pain of shingles. It is not a narcotic drug and has no problems of dependence or addiction.
- Some members said that they wanted to get involved with the NIH study at Bethesda. There was no news from the NIH this week. They are still planning to begin seeing patients again, the end of the summer. Meanwhile they have been studying the blood/tissue/test results from the patients who have been there already. Members expressed how grateful they are that the NIH is doing what they are doing.

- One member is using a fentanyl patch (Durogesic) for pain. This is a narcotic drug which is given through the skin. The member is finding that a tolerance is building up, and so more is needed.
- Members mentioned the treatments that they are on. One member has now been able to stop taking any drugs for ECD! Members also said whether they were still working.
- A member, who has lost her sight due to the ECD, told us that she has now learned the whole alphabet in Braille. Weight loss has also occurred. Her fiancé is trying to get his weight down too!
- A member had had a recurrence of a troublesome leg itch. But using the area as the injection site for an Intron shot, had made things better!
- A member told us that the principal problem is shortness of breath. Also there has been a lot of worry concerning the member's daughter, who has had a recurrent lung problem. The doctors have said that one lung will not be a problem anymore. The condition that she has is usually seen in tall, young men.
- Many members thought that it was good, and useful, to keep their doctors informed about any new findings related to ECD. Some doctors use the ECD Global Alliance web-site as an information source. The Alliance does not have an "official" Facebook" page although there is one associated with ECD. One of our members has a FB page called "Defying a Frightening Diagnosis".
- One member is being sent for therapy for the second time. Lots of tests but no explanations. She has been on all different kinds of medicines for pain, and has built up a tolerance, so that nothing really helps at this time. She has done well with the shots apart from the area getting really red, and sometimes being bruised for about a week. She has been very tough through all of this, and her family is very proud of her. Other members suggested that her doctors could contact Dr. Kurzrock, at the MD Anderson Hospital in Houston as she has much experience in treating ECD.
- A member's wife has been unwell, and has 3 appointments with doctors next week. Luckily, her son is fairly close by (by American standards that is. Only 5 hours away!).
- A new member is finding it difficult to settle on a treatment. For many it does seem to take a while to find a treatment that halts the progression of the disease. But, many do find a better quality of life eventually.
- After the Chat had finished, a member came on and left a message. She had returned the night before from a holiday in the Greek Islands. There were not very many railings to hold onto, so her boyfriend had been her "donkey around everywhere!"