

Summary of ECD Global Alliance Chat on 15 December 2012

6 Attendees

- A member asked about other's experiences at the NIH. One member had just made a second trip, and enjoyed it, AND found out that things were stable. The member, asking about the NIH study, was advised to go to Bethesda. It would just need an email, to Dr Estrada, to express an interest in being part of the study, and then, he will send all the information and applications needed. It was suggested that the member could get any help, needed with filling the applications, from others, who have already been. One member might even be able to drive down to Washington for a meeting! Two members, who live on different sides of the Atlantic, have recently been at Bethesda at the same time, so they met up. This was for the second time. They had first met a year earlier, when one of them had come over from Europe for the study.
- A member, who has been having severe pains from the scapula down the arm, came on, but only managed a brief stay due to the pain. This member asked whether anyone would like to try to co-write an inspirational book, to help "folks to keep fighting after a scary diagnosis". The member suggested that it would be possible to come up with ideas, and email them back and forth. Some members have had to cope with many problems, and would have some useful views to give. One member said that they would like to help, but there are "not enough hours in my days".
- A member, whose daughter got married recently, is enjoying the situation. Things are better for her. She has had a lot of problems, to deal with, due to the ECD.
- One member needed to go and fix the Christmas lights, which weren't working, but stayed to Chat!
- A few members told us that they had not, yet, got fully organised for the holidays. Expeditions, to buy presents, were needed.

- A member has a wife who drags him off to a hotel with a spa. And "Very nice ladies" massage his back, and then he can walk. He was congratulated on having such a helpful spouse!
- A member came on, who is in her late teens, and is going to NIH this week. She has an irregular bone marrow, and bone pain. Chest pains were the first problem. There are lesions in her brain, too. Other members on the Chat also had brain lesions, often confirmed by brain biopsy. Her treatment is; interferon weekly, zometa (for bone pain) once a month, daily gabapentin, and daily topamax (for dizziness). Because she was having chest pains, and palpitations, the doctors used a cardiac catheter, to do an ablation of the part the heart, that was the cause of these problems.

She is in her second year of college, and is studying accounting. She is going to the NIH for the week before Christmas. Having just finished classes, this was the best time to go, and she thinks that she will be the last one for the NIH for 2012. She was warned that she will be VERY busy. Her mother and aunt are going too, and it is an 11 hour drive. She was advised to take the opportunity to see some of the sights, while she is there, providing that she is well enough.

- We were reminded that one member is now on no drugs for the ECD at all! Previous treatments had included interferon and prednisolone, but cladribine (2CDA) seemed to have "really made a difference". She is now doing very well, although her walking and balance would probably be better, if she hadn't lost her sight due to the ECD.
- A member came on after the Chat had finished, telling us that they had "just got back from the Mayo Clinic in MN".