

## Summary of ECD Global Alliance Internet Chat

12 May 2012

9 Attendees

- A member came on who has recently been having stomach problems. These have improved enough for the member to start having harp lessons again, and eating is not so difficult as it had been.
- There was a discussion about donating bodies, or tissues, to medical institutions, doing ECD research. The NIH and Texas Children's have said they would like tissue samples. It was thought that the MD Anderson team is also interested in tissue donations. The way that the doctors are requesting tissue donation is very specific. This is something that needs to be set up in advance with all the medical teams. You could have your doctors contact the researchers directly, or contact Kathy at [support@erdheim-chester.org](mailto:support@erdheim-chester.org) if you are interested in doing this..
- Dr. Estrada-Veras reports that adult patients, who can only submit tissue because of their medical condition, can now be accepted into the the NIH ECD Natural History Study. The NIH is still on track to see additional ECD patients beginning the end of the summer.
- A member has recently had surgery to remove some cancerous growths from his face, which has required a lot of stitches to be placed. The doctors have not said what type of cancer it was yet. A few years ago squamous cell cancer was removed from his arm. He has good days and not so good days.
- A "sad" member who is a bit of a "cloud nerd" said that ***cloudappreciationsociety.org*** was a good site to visit. LOTS of great pictures, that members had sent in (even a fair number of pictures of clouds above Lake Tahoe, just for TahoeGail!).
- Last week, a member (who shall remain nameless) had not come Chatting, because he was already in bed! He claimed that he had been "tired out" after a day at a Cooking School doing Fish Recipes! He was asked about the recipes that had tired him out so much. "Pan fried tuna steak, asparagus, and sauce vert for lunch. Red mullet, sea bass stuffed with spicy couscous "en papillotte", and marinated sardines to take home. All very nice. All the fish started off whole, and had to be de-scaled, filleted and beheaded!
- Two members joined us, who have both lost loved ones due to ECD, fairly recently. They were welcomed onto the chat. Both are managing to do some things that they like to do, but it is, understandably, difficult.
- There was a brief discussion about the Powerball/Gyro Exerciser that a couple of patients have. One member said that he had scored 7697 on his Powerball. The other had not managed to "get the darn thing to go!!"
- A member's son (non-ECD patient) has recently had neck surgery, and will be off work for 6 weeks.
- Another member is doing Foster Parent classes. The 1st part is finished, but it has become very difficult. There always seems to be more to do. They want his wife to switch to day

work, although this will mean a significant reduction in income. They have also been "concerned" about some of the medication that he uses. They haven't been worried by the Intron, or the fentanyl patches, just clonazepam, which is taken to reduce leg muscle spasms.

- There was then a discussion about addiction. This may just mean that something is difficult to stop, and not mean that you are "hooked" on it, like speed or heroin. Tea and coffee are addictive, as is chocolate!! Cheesecake joined the list of addictive substances too.
- A member told us that he may have found someone to mow his yard. It was pointed out that then he can then, sit outside and watch, eat chocolate and cheesecake, and wash it all down with tea and coffee!! While the yard gets mown by SOMEONE ELSE!!
- A member came on late. He had had company and so he couldn't come on at the normal time. He had suffered a fall. Bruised, but not broken, and it is getting better.
- Another member came on who had "had a very nice day at an Irish festival". The women of his house had been off buying stuff for the impending wedding.