

Summary of ECD Global Alliance Internet Chat on 09 Jun 2012

7 Attendees

- A member came on before the Chat "proper". He has a daughter with ECD. He told us that he was likely to miss the Chat, but for a good reasons. He had other things to do that didn't centre on ECD! He told us that his daughter was doing well emotionally, and, although her sight isn't improving, she is using the sight that she has got, better. She took a photo of her fiancé yesterday, with her I-phone, and it is on Facebook. The phone is not cheap, but it is a godsend to a blind person, as she can go on-line with it, and it talks to her, like her computer does. "A link to the real world".
- A member who had not been with us for a long time, came on and was welcomed back.
- A member asked, how long had the other Chatters had ECD for, and whether they were still able to work.
- The member, who had not been with us for a while, told us that his wife had had ECD for 20 years, and she could not work. She has recently died.
- One member said that they had ECD diagnosed 8 years ago, and had been retired for the last 5 years.
- Another member had been diagnosed 7 years ago, and also could not work.
- There was one member, who was diagnosed 16 months ago, and who is still working full-time. But the member thinks that there will have to be a reduction in hours worked soon.
- One member could manage some wood-turning, as a hobby. Some of us have been sent pictures of the results.
- Some members then gave details of their trip down "ECD Lane", as they "progressed" towards getting a diagnosis!
- We all agreed that we had different symptoms, and some symptoms were shared. Pain, stiffness in limbs, difficulty breathing, slurred speech, poor balance, and double vision were all mentioned. Also, a general tiredness was common.
- A new member had recently had leg surgery to a non-cancerous tumor, and was just starting to walk again, after 3 months. A member had been found, at the beginning, to have a growth on the pituitary gland. This was non-cancerous, and initially thought to be an adenoma. It was later described as a xanthoma. These are

non-cancerous collections of cholesterol, which cause problems by their physical presence in your system. They just get in the way (like men)! The yellow bits that appear under people's eyes are xanthomas. One member had had a large one surgically removed, and also had some others "frozen off, with some sort of acid". One lucky member found that the xanthomas just faded away, as did some swellings in the tendons of the little fingers!

- The research at the NIH in Maryland, was mentioned, and members were encouraged to try to go there.
- A member asked why the Chat line only operated once a week. Some members said that they keep in touch in the meantime by e-mail, but these don't go to the whole group.
- A member had been troubled by sores all over her body, but these seemed to be clearing, now that treatment had been started.
- We were told that a member's neurologist had written an article about ECD, and a patient (who is the member!), which is published now in Journal of Neurology. Fame, at last! Another member's case had been used at a conference by an ophthalmologist.
- The member who recently had given the "Lesson" at church said that it had gone well, and that it would be on Facebook on the Vine of the Mountains page. Back and kidney pain had been a problem yesterday. Contrast had been given during an MRI scan of the kidneys.
- A member recommended that we should ALL read an essay written by Stephen Jay Gould, because we have probably all come across the "median survival of patients with ECD is 3 years" statement, and have been scared by it! The essay is called "The Median is not the Message". Not too long, nor difficult to read. Google it, and you will find lots of entries. It tries to explain about the difference between "medians" and "means" which is important to us all. (see http://cancerguide.org/median_not_msg.html)
- One member excused themselves from next week's Chat. They are going to a wedding party.