

Summary of ECD Global Alliance Internet Chat 14 April 2012

8 Attendees

- A member had been given a "Powerball" for his birthday. This is a handheld gyroscopic device, used to help exercise and strengthen the wrist and forearm. Previously, another member had mentioned a "gyro exerciser" which her son used. As with many "trendy" bits of kit, the kids can use it straight away, and the grown-ups can't work it, at all!
- A member is having trouble walking. A combination of bad balance, and stiffness of the muscles, means that tripping is a real problem. Carrying on a full time job is not at all easy.
- A member, living in Norway, has recently been contacted by another Norwegian with ECD. Details of our group were passed on.
- A new member joined the chat. He is from Phoenix, 46 years old, and was diagnosed with ECD in 2008. He attends the Core Institute in Gilbert. He was welcomed onto the Chat. Members were invited to introduce themselves, and to give brief versions of their "story so far".
- A question raised as to how many of us had ever met any other ECD patients. Some of us had never met anyone else at all, and a few of us had managed to meet over the last few years.
- The NIH team is doing some genetic testing involving family members.
- A member has been worn out by a week of routine hospital tests.
- A member asked whether anyone's vision had got worse. The only response was from one member, who said that his gets worse when his glasses get grubby, until his wife notices and she washes them! Then the vision is fine!
- It was said that Histiocytosis is now on the list of diseases that Social Security use. Hopefully that will make the claiming process easier
- A member came on who had not been with us for a while. Gall bladder surgery had got in the way of any Chatting! She and her family are getting along alright, after their loss. They can now recognize signs of ECD from 4 years ago. There was double vision, tiredness, and incredible thirst.
- One member is trying to schedule a visit to the NIH for a week in September.