

Summary of ECD Global Alliance Internet Chat 8 Sept 2012

8 Attendees

- Quite a few members mentioned that they were having problems with their balance. One member has found that his balance is getting worse. Many of us need to use various parts of our houses/flats to steady ourselves. Some members also have other difficulties to contend with, such as extremely poor vision, drug side-effects, and effects of Botox that had been given for spasm in the legs.
- A member is getting married on Oct 6 and the wedding plans are all coming along well.
- Some members mentioned the NIH research program. Two are going soon, and another is going back for a review visit, a year after the first visit. One member has very poor eyesight, and they are putting her and Mom in a room on site! Another ECD patient, from Norway, may be going to the NIH too.
- A member, whose son has ECD, said that her son's vision changed quite a bit this last week. He went and got a new Rx for his contacts, and then called today and his vision had changed back. A member, who has just been on vacation, had had nice warm weather and been able to get out on his scooter, and visit some nice places.
- A member asked whether other members are troubled with depression. Some members said that they were having difficulties. One member finds that the depression becomes worse if medication is reduced. Another member said that medical insurance would not cover the costs of generic Prozac (Fluoxetine).
- A big storm then arrived at one of the member's home. The advice is not to use laptops during these storms so we all said goodbye.
- Dr Haroche has telephoned a member, who previously had been to Paris and was seen by him. Dr. Haroche asked whether some tissue samples could be sent to his lab. They are trying to trace a particular genetic mutation.
- A member, who has changed to an easier job, was asked how it was going. Better, but very busy being a secretary. A member asked whether typing was OK. Keyboards, with larger than standard keys, and better colour contrast on the key labels, were mentioned. One member has a large (billiard/pool ball sized) trackball, instead of a mouse. Luckily, typing is not a problem for our new "secretary".
- A member, who had sent an interview, that they featured in, to Dr Estrada, had been contacted, and told that he had liked it.
- A member told us that his wife (non-ECD patient) has had hard time this week. She had bad pains; our member was worried that she was having a heart attack. She was admitted to hospital for two days, and was told that it had been something to do with her blood pressure.