

Summary of ECD Global Alliance Internet Chat on 14 July 2012

10 Attendees

- Two new chatterers introduced themselves. One is only 19, and it had taken 5 years to get a diagnosis. Still in school, and managing a few hours work a week (with an understanding boss!). There has been some improvement since starting treatment.
- The other new Chatterer is 75 and was diagnosed a few months ago. There had been some blockage to the renal arteries, and a kidney biopsy gave the diagnosis. Members exchanged information about where they lived, and where they had gone to get their diagnosis.
- The member, whose daughter has recently had surgery for a lung problem, told us that her daughter was making progress.
- A number of members mentioned "peripheral neuropathy". This is damage to the nerves that supply the bits of our bodies that are furthest away from our brain i.e. the longest nerves in the body. A few members had this problem, ranging from cool, or cold feet, to pains or numbness. It can also cause abnormal sensations; like something cold feeling wet instead. Tripping on rugs or towels on bathroom floors is a problem. A few members said that they had difficulty lifting their feet to let them walk free of the obstacles.
- A member is keeping a coral reef aquarium, and getting the sort of fish, that can be seen by our member who has very little sight due to ECD.
- We were joined by a member whose wife recently died from ECD. He has recently turned 60. He is also about to be ordained as a deacon, for which he has been doing a lot of studying.
- We were reminded about the NIH study, and that they wanted as many of us as possible to participate.
- A number of members mentioned that they had problems with their balance.
- One member is being seen by a neurologist to decide whether a shunt is needed to relieve hydrocephalus (a fluid build-up around the brain). Also a bowel examination is due and the "Colyte" bowel preparation has to be taken.
- There was a discussion about the benefits of wearing magnets to ease pain. Some members have found them to be useful.