

Summary Of ECD Global Alliance Online Chat 25 August 2012

13 Attendees

- The Chat started with usual greetings. It was particularly pleasing to welcome back 2 members, who we have not chatted with for quite some time.
- A member, who has ECD, has had a 2 week course of in-patient, physio- and occupational therapy, to good effect. Floor exercises, rubber band stretching work, and a recumbent exercise cycle are used at home. Balance has been poor, and the leg muscles were weak. A walker has been used for more than 2 years, and wheelchair when out and about. The leg muscles have continued to weaken. The therapy helped to get started on a program to increase the leg strength, and also tried to work on balance. There has been some improvement already. The physiotherapist always says that "walking is the best exercise because you have to carry your own weight".
- A member told us that, although exercise has not been a favourite pastime for the last 10 years, it seems to help a lot. Free weights and the use of a stationary bike were mentioned. A member, who has been going to a spinning class, is continuing to go 2 or 3 times a week, and is also doing some weightlifting!
- The physio- and occupational therapists were praised for their work in maintaining ability.
- The member who has had botox injections in the legs, to try to reduce spasm, is going to see the doctor involved next week. The botox has not had the desired effect. We were pleased to hear that the member's job was getting a little easier.
- This member has already been to the NIH, and is keen to go again. Dr. Estrada-Veras has agreed on November 26th, so some cheap plane tickets have been bought, and the travel coordinator, at the NIH, has booked a hotel for the family members who are coming too. This will be the first member who is returning. There is not much happening in the member's own country, so organising things for herself is the most productive option. Another member is booked in for a first visit to the NIH at the same time, so they can keep each other company!
- Our Antipodean member came on, and told us that he was well. Spring is approaching! (editor's note: Antipodean refers to Australia in this comment...the editor had to look this up!)

- A member, who lost his wife to ECD, came on. He had just come home, from staying in his cottage, for a few days. When at home, he goes to a local fitness centre each day. His leg has been painful, and he thinks that he may have pulled a muscle while walking.
- A member came on who had had a bad back pain all night. Another member used to have some serious back pain, that would wake him up at night, but, thankfully, this hasn't happened in about a year.
- A member came on, who has been having tests prior to surgery. The purpose of the surgery will be to try to return function in his kidneys. Investigations this week, including an angiogram, have been tiring. The surgery will be a by-pass of both renal arteries, with a 5 to 7 day stay in hospital, and about 6 wks for full recovery. The surgeon thinks that the blockage of the arteries is more likely to be age-related, than due to the ECD.
- A member has been having bad headaches. At a recent visit to the neurologist, he was told that his hydrocephalus (excess fluid in the cavities inside the brain) had not gotten worse. He is going to get a further opinion from another neurologist. The placing of a shunt (to drain away the excess fluid) is being considered. Another member also has hydrocephalus, and has also considered shunts. The doctors have mentioned that shrinkage of the brain, when the fluid is drained, may cause a subdural haematoma.
- Our wood working member was asked how things were going. He had just made 16 old style Christmas lights out of wood, and is now making a plywood bowl and a lighthouse. Things have been going a little slow, because he feels more exhausted, and has been having bad leg pain at night.
- Some members, who had suffered bereavement due to ECD, discussed problems sleeping, that one member was having.
- A member came on after the Chat and apologised for missing it. This member had had some steroid injections in their back two weeks ago, that seemed to help calm the "sharpness" of the pains. Therapy has started and some stretches have been suggested to, hopefully, help. The member has to go back to work after two weeks of resting their back.