

Summary of ECD Global Alliance Internet Chat on May 11 2013

8 Attendees

- A member reminded us that they had fallen, about a month ago, and broken their left hip. The member's wife had also fallen, and needed a number of stitches in her left leg. The hip has been painful, but morphine medicine is helping, and the member is beginning to exercise.
- A member left us a message to say that they were going to be in South Carolina for Mother's Day, and for her birthday too. This member has been having physiotherapy for a leg problem. This has improved things, and he has been discharged from physiotherapy.
- A member's son (the son has ECD), has just been to Houston, for his 6 month check-up. He is doing well, and he is still working for the county, as a social worker. His employers have requested a note, from his Dr., as to his limitations. His teeth, which have been a real problem, have been fine, and no more have broken off.
- A member gave us an update on the condition of his father, who has ECD. He is doing pretty well, and is starting on his 9th week of Pegasys, along with dexamethasone. Cognitively, he is more like himself; his memory is getting better, he speaks and writes well, and is more engaged and interested in things, like he was years ago. He believes his vision is improving. Walking/balance may be improving, too. He has said that, this is the best he has felt in a long time.
- A member, who has recently changed from interferon treatment to Low Dose Naltrexone (LDN) said that they seem to be coming out of their "nest". The member had felt like they had stayed at home all winter (besides going to work) but is now becoming more social again. This member has the opportunity to go to a rehabilitation centre, for MS patients, before a summer vacation that has been booked. Others on the Chat recommended going to rehabilitation centre.
- Members discussed whether they would be going to San Diego later this year for the Patient and Family Gathering.
- A member has been very busy taking care of her husband, who has had major surgery, and then will need cancer treatment for 4 to 6 months.
- The member who was having his disability scooter repaired, after being run into by a car, has had it returned. Another member with a battery powered scooter managed to blow the battery while trying to go up a steep hill. Luckily, there was a fence too cling to, and the in-laws to push!
- A member, who has been having physiotherapy to help with balance problems, has become "pretty stable" again. The member is managing better now than in the winter months.
- A member is about to start speech therapy, "to check I've not choked on any pineapple."
- A member came on after the Chat. They had been out walking a neighbour's dog. The neighbour has just had a hip replacement. This member has been having more pain this week, because of the rain. There is a visit to the doctor this week, for a Zometa injection and to talk about pain. The medications are, already, being used at their maximum doses. Chemotherapy will be the next step.