

## Summary of ECD Global Alliance Online Chat

23 Mar 2013

6 Attendees

- Some members told us of recent problems with their computers. They said that they were glad to be back "Chatting".
- A member, who has just been on a "birthday break", said that he had a good time. His disability scooter/ Harley is still "poorly" and bent after the recent RTA. The Harley is being collected by the manufacturers soon.
- Some members had got snow at the moment, and others have it forecast. And others had "a nice sunny day".
- A recently married member told us that things were going well, and her husband will soon be busy taking baseball pictures, when the season starts.
- A member has started to advance in physical therapy. This member is still able to work, and stayed late yesterday. The schedule it to work a double shift tomorrow.
- Another member told us that her son, who has ECD, has also, been doing physical therapy and finds that the machines have really helped.
- The SPIT FOR A CURE campaign was discussed. Dr. Allen, at Texas Children's Hospital, is doing research, looking for a genetic cause for ECD. He would like anyone with ECD, who has living parents, to sign them up to spit in a tube, and, then, mail it back to him. Members, who have already done this, said that it was easy to do, and encouraged the rest of us to take part in the program.
- A member, who has been struggling with work, luckily, has an understanding boss. If the member doesn't feel able to cope, she informs the boss and goes home. The member is trying her hardest to keep pushing herself, and to stay active.
- The left leg, of a member, has started hurting, and become weaker for an unknown reason. It "feels muscular", and is stopping the member from staying active, and from getting his new dog his exercise. The doctor is being visited later this week.
- Another member had had to abandon walking her dogs, and had to be picked up half way into the walk because of knee pains and tiredness. The dogs are a border collie/spaniel mix, and a husky/shepherd mix, and their names are Cocoa and Snickers.

- The member, with a new puppy, told us that it was a Yorkie/Terrier mix, and it was called Benji (already named when they got him).
- While on the subject of dogs, a member told us that he had had a giant poodle (= standard) called Tom (although his real name was Lingrebar Black Knight Tomas, because he was a pedigree dog!!). 100 pounds of muscle and stupidity, with no fat on him at all! Tom had had to be rehomed. He would knock/pull the member over.
- After we had finished a member came on late. The good news is that she was late because she had managed to work an extra afternoon shift.