

## **ECD GLOBAL ALLIANCE CHAT SUMMARY CHAT ON 17/12/2011**

### **8 Attendees**

- A member who has recently lost his wife due to ECD, said that he felt rather like an outsider. He was assured, by the other Chatters, that he was definitely NOT an outsider. His experience of this illness is valuable to us all. He has recently had hip surgery, and planning to do more exercise. Bowling with the grand-kids is part of the plan. He had just got home from Christmas shopping with his son. We were told by one member about a 91 year old man, who has had surgery to both hips, and walks 4 miles a day!
- A member, who has been having trouble with weeping legs, had had a bit more trouble, but things had cleared up now. Bell ringing is a passion, and there was a recent concert as well, so it was a lot of time on her feet.
- A member with back pain will be starting therapy in the pool this week.
- More general ECD news from Kathy. The seventh patient has just been to the NIH, and Dr Vaglio has been sent another set of records.
- There had been a Board of Directors Meeting on that morning and it had heard about the work our Director of Development is doing to help raise funds to allow the organization to carry out its mission. Rare Disease Day on Feb. 29 is just around the corner with a lot happening in the DC area.
- Another member had to leave quickly. He had just been rung to be told that his sister-in-law had tried to commit suicide. Many members offered their sympathies and sent their prayers.
- Another member, who has been suffering with back pain, has found therapy to be helpful, although this is not pool therapy.
- Finally, one member admitted to doing some "Christmas Baking", but it was only munchies all day!