

ECD Global Alliance Internet Chat 07 Jan 2012 Summary

11 Attendees

- Members started the Chat with the normal greetings, and enquiries as to how the holidays had been spent.
- A member who does woodwork for a hobby has made a wooden ring. It looks very good, but is very difficult to size. He has to do things in sections, and sits down for some of the work. Another member said that he is unable to spend too much time at the lathe anymore.
- Kathy is about to go to NIH and "shadow" a patient through the study. She will be able to meet another patient, and learn about what it is like to participate in the NIH study..
- One member has started 2 new jobs! ; 60% as a secretary, and 40% as a project manager. This is in a hospital, but she would prefer to be using her nursing skills. She is looking at other jobs in the same building, and has applied for one in a unit for pathological obesity. Interferon treatment makes her tired. Evenings are spent sleeping. Another member agreed with this picture of tiredness on interferon.
- A member who has been trying to sell his house in Florida, has made a sale. He is now in the process of packing everything up! He also has back pain, and is now going to try a 4 wheel walker. He is still having physiotherapy.
- One member had had a family get together in the week leading up to Christmas. A good time had been had by all. The member had enjoyed feeling good, after feeling bad for so many years. He had recently been to NIH, and they had found that the fibrosis behind his eyes had lessened markedly. He felt that the side-effects from interferon were a price worth paying. At Christmas, there had been a one-year old child in the party, who played with sea-shells to the exclusion of her presents. Another member had had a 6 month old child, brought to see her for New Years. He had found the member's shoe-laces to be fascinating! It was generally agreed that young children would do this sort of thing, and that "boxes" were a good bet as playthings.
- Our members who are getting married fairly soon are trying "to work off the holiday food!" They are planning to get involved with the upcoming Rare

Diseases Day (Feb 29), with the suggestion of getting information posters to the hospitals, so they can be displayed.

- A member came on who has had some back problems. She is still having physiotherapy which is tiring. She goes to the hospital out-patient department 2 or 3 times a week. She has been working on her core muscle strength, and is now beginning to work on auxiliary muscles. She can already see some improvement. She got out of condition when she was looking after her sick husband.
- Another member extolled the benefits of exercise. He has found it a great help, during the 10 years that he has been unwell. He walks the dog daily, and has 2 sessions a week on a stationary bicycle, and does some free-weight work too. It was generally thought that this was quite a rigorous workout schedule!
- The mother of a man with ECD said that he uses a stationary bicycle and a gyro exerciser. Wikipedia has an entry for these, and they are available to buy through the internet.
- A member had managed to spend holiday time with his family, by moving about from house to house.
- One member had not been able to get on-line during the chat. After venting his spleen on the subject of computers, he said that he won't be with us next week because he will be on the flight to NIH.