

## **ECD Global Alliance Chat Summary**

**26 Nov 2011**

5 Attendees:

- One member discussed his wife's situation, saying she had to return to hospital and he was concerned.
- There has also been some bad news from Australia. Our member over there has been very ill for some time, and has not improved despite trying many different therapies. The medical team is now going to take a "palliative" approach to her care. We all hope that this will give her and her husband the opportunity to spend some good time together.
- A member has a date for NIH of 15<sup>th</sup> Jan and is excited about the trip. A recent doctor visit showed that the "bad" cholesterol was great, but that the "good" cholesterol needs to climb. More fish, nuts, and fish oil capsules are going to be on the menu! Luckily, fruits and vegetables are already favourite foods!
- Another member had had an initial contact with NIH but they had not got back in touch yet. It was suggested that contact should be made again.
- Another set of records are being sent to Italy. We think that Dr Vaglio now has 16 sets.
- There was a discussion about powers of attorney. This was started because a member had been thinking about what the future might hold, and how his loved ones would cope with the efforts involved in, and the costs of caring. It was said that it is probably best to think about these matters, and to have a plan of action. A Powers of Attorney will operate differently in different countries, and so we will need advice from people who "know the system".
- A member was concerned about holiday visits with families. The book, "Men are from Mars, Women are from Venus" was mentioned. One chat participant had read the book, but not managed to get her husband to read it, and 2 male participants could remember seeing the cover at the book store, but neither had bought it!