

## **Summary of ECD Global Alliance Internet Chat**

**13 October 2012**

### **8 Attendees**

- A member, who has just been to the NIH, told us that he had had a good time. He thought that it had been worth the 41 tubes of blood that he had left there. Another member, who had been to the NIH, told us that they had left 50 something tubes, and another member had had to leave 50+ bottles on a visit to Paris, to see Dr Haroche. The overall experience at the NIH had been good, but going into the MRI scanner had brought on claustrophobia, and required some sedation. Despite this, the member would still, gladly, go back if requested.
- This member, since returning from NIH, has made a LOT of chicken & vegetable soup this week. We were told that one of our Board of Directors members, Rachel, is thinking about doing a cookbook\* as a fundraiser for the organization. If this goes through, she will need recipes...so it would be helpful to keep the good ones handy!
- Our newly-weds both joined the chat. Married life is suiting them well, and they are both enjoying it. They tell us they have got through the first week "without killing each other!" ☺ The member of this couple, who has ECD, is about to go to the NIH, and another member of the Alliance is returning for a second visit at the same time. So they will be there together! Aaaah!
- A member told us that spring was starting in Australia, with the rhododendrons already looking good.
- A member is awaiting some tests. Her doctor has consulted Dr Janku already.
- A member, who has been finding work rather difficult, has been promoted to a new position as assistant leader of a psychiatric ward for elderly people. But today she had managed to fall out of the shower and to hit her head on the toilet bowl! This led to a discussion about grab bars/rails. It was agreed that these were a good thing, and many members already have them. Some members have not been allowed to return home from

hospital until after the bars have been fitted. Some members have removable suction bars. They can be used when away from home, like in a hotel. It was suggested that all homes should be built suitable for such rails to be installed. It was also suggested that homes should have ramp access, or, at least, be designed so that can be easily added if needed.

- We were told that the ECD Global Alliance Board of Directors will be meeting in Houston in November. About 10 research doctors from the US are planning to attend at that time for a short meeting. Hopefully, this will be the beginning of what could be a very fruitful conversation, as the researchers share their ideas and findings.
- Members congratulated the board, for managing to get such a meeting organised. Kathy reminded us that the organisation belongs to us all, and, if there is anything you think the ECD Global Alliance can do to help you, please let her know. The input from our members is always appreciated.

**\*More details to come concerning the cookbook fundraiser. Members, family and friends will be invited to participate!**