

## **Summary of ECD Global Alliance Internet Chat November 18, 2017**

6 Attendees

- One member had been at a hospital in Paris for four days, undergoing tests. They had lots of blood samples taken (20-30 bottles!) and had a hairy kidney biopsy.
- One member who had attended the recent ECD Global Alliance conference said that they had enjoyed it and that it was good to put faces to names.
- A patient has written some poems about their experience of having ECD. They said that they thought that having confidence and a good mood was important in coping with ECD.
- Several people on the chat discussed their lack of energy caused by ECD. Another member said that even preparing a simple meal was often painful.
- Everyone wished each other a Happy Thanksgiving.