

Summary of ECD Global Alliance Internet Chat

20th July 2014

3 Attendees

- A “select” group who kept it “short but sweet”.
- The weather was discussed. Hot in the UK and stormy, humid in the US. The UK member told us that pajamas were too much to wear. Other members thought that this would be quite a “picture”.
- We were told that a US member was having balance issues that seemed to be getting worse.
- Another US patient has recently had a good report of a recent PET CT scan. Her bones look “much better”. She told us that she feels a lot better than she did before treatment.
- The member who recently fell and broke a rib, is getting much better, with little pain. He is shortly “off to see the wizard”, who is a Hematology Professor in Leeds, UK. This doctor is going to be at the ECD-GA conference in autumn. He told our member that he has about 15 ECD patients now!! The chatters mused about how many of us there are in the ECD club.