

Summary of ECD Global Alliance Internet Chat

4 Oct 2014

10 Attendees

- Members talked about their experiences at Bethesda. They all said that things had gone very well. They mentioned that they had enjoyed "putting faces to names". Next year the convention is being held in Houston (where one of our members lives). The following year, hopefully will be in Paris, France.
- It was good meeting with a lot of ECD interested doctors. Dr. Haroche from Paris was singled out for mention. One member was pleased because she had her photo taken with him! The Caregiver's session was also praised.
- The member who has been "learning" to play the trumpet has had to give it up. Apart from being fairly talentless, he fell and broke a rib recently. This was painful and made practice impossible. He has decided not to resume "trumpet torture", although the rib is now healed. He and the member who is a "proper" trumpeter in a "proper" orchestra, talked about various recordings that they enjoyed.
- Members talked about how they are doing at present. Two are in the middle of chemotherapy courses, but doing OK. Lack of energy was discussed. This problem affects many ECD patients, but there is no particular treatment or cure.
- Some of the US members raised the possibility of doing some sort of tour. Perhaps some music and comedy, but NO dancing!
- Our member from Norway told us that she thinks that there are now 4 Norwegian patients, and that two are on Vemurafenib (V), with a third starting soon. The treatment for the fourth patient is unknown.
- Members then began to ask one particular member whether she had now been elected Mayor of Bethesda! She had not, but was advised to keep campaigning, maybe run for Mayor of Houston, or even President of the US (when she gets to be old enough!).