

Summary of ECD Global Alliance Internet Chat

12 June 2014

4 Attendees

- A member left a message before the Chat started, saying that he was going out to eat this evening, and might not be able to Chat.
- There were only three members on the Chat. Weather must have been good most everywhere (it certainly was in the UK).
- A member said that he had just had a good visit with his daughter and her family.
- One member is just about to have a week with a fair bit of "doctor time" in it, and one has had a lot of "doctor time" just lately.
- All today's chatters will be going to Bethesda this year. They are looking forward to this, especially for the chance to "put faces to names".
- A member is probably going to go to the NIH in the fall. One of the Chatters had been there in Oct 2012.

It was a very busy week, moving from one test to another, but "They treated us like VIP". He wanted to help others, and they helped him with some sleep issues. They took 41 tubes of blood over 3 days! [Summarizer's note; Dr. Haroche's bunch in Paris took 37 bottles on the first day off me, and another 13 on the next morning; so watch out!]

- The member who hopes to go to the NIH in the fall is in the process of getting all the records that they want. The remaining item for him is all of the pathology for the blood work. This has been done every two weeks or so at MD Anderson.
- A member has had problems with her leg recently. She had a PET CT this week, and got a good report, but still has the painful "knot" on her leg bone. This is about the size of a baseball. If she walks, it swells more and hurts. She gets shooting pains "any time". She uses a cane to help, and a wheelchair for any distance. Dr. Janku is puzzled about it. He touched it and she JUMPED so she reckons that he understands that it hurts! She will be having an MRI soon.
- Another member said that he, also, had pain in his legs, below the knees, under the skin, and swelling. It hurts when something touches his leg. A member said that he hoped that he would not have similar troubles. So far his symptoms seem less severe than most. He

wondered whether he is seeing the benefit of an early diagnosis. It was said that we all have some of the same symptoms, and we often have something different as well.