

ECD Global Alliance Chat 08 October 2011

4 Attendees

- A member whose son has ECD told us that he had just completed his stay at the NIH. He had received a schedule for his time there 5 days before travel. He was met by a driver at the airport, and there are regular shuttle buses to and from NIH. He had found it a very pleasant stay. A good number of tests were performed between 0730 and 1600. A lot of doctors who were interested in his case and his illness, came to visit. He has said that the bronchoscopy had not been difficult. He was sedated for the procedure. His results are going to be passed on to Dr Kurzrock in Houston.
- We were reminded that they need as many volunteers to go to Bethesda as possible. In Italy, Dr Vaglio has only had 10 sets of records sent to him so far, so he needs more input from us as well. It was suggested that even records in different languages should be sent.
- A member who has been recently unwell with a Clostridium difficile infection said that he was much improved since being on the antibiotics.
- Although there is still some back pain, the member is managing to walk with a walker.
- The doctors at NIH are wondering whether there might be a genetic component in ECD, and are arranging for some blood work to be done on Larry M's parents.
- Dr Vaglio's e-mail is augusto.vaglio@virgilio.it