

Summary of ECD Global Alliance chat held on Saturday 6th August 2011

10 Present

- Before the Chat started, a member had posted a long piece in support of the ECD Global Alliance. It was pointed out that the Global Alliance is the only organization known in the world dedicated completely to ECD, and that the Global Alliance has done more for ECD research and support than any other organization.
- There was considerable interest in the, recently announced, NIH study at Bethesda. A number of members said that they would like to be involved. The first necessary step is to contact the study team. Kathy has offered to make an e-mail introduction of members to Dr Estrada-Veras, so that he can then make direct e-mail contact. They will need a certain amount of time to collect the necessary records, before scheduling your stay.
- Both parents, of a member living in Europe, are US citizens, and the member is going to apply for a US passport.
- The NIH at Bethesda will only want to take one patient per week. It will be a 5 day stay so that all the necessary investigations can be done. There will probably be “passes” out during the stay!
- The local airports were then discussed. Dulles, Ronald Reagan National, Baltimore-Washington International are the nearest. Of these, BWI is the furthest away, but there is a free shuttle to the NIH. This has been use by a members going to the NIH and works well.
- The NIH holds a lot of information about travel possibilities and would be a source for members travelling.
- It was suggested by a number of people that Washington is definitely worth a visit while you are there.
- Members were reminded about the current fund-raising activity. It was suggested that notifying friends, that use Facebook, is a good method of raising contributions.
- A member continues to have a lot of difficulty due to fluid seeping from her legs. Compression hose have not solved the problem so far and the skin is irritated.
- A 3 day hospital stay, steroids and a blood transfusion allowed one member to dance out of hospital! He had been too ill to even walk in!
- One member is seeing a doctor shortly about pains in his back. He thinks that injection treatments will be suggested. Another member said that a parent had had back trouble, and found that the injections were a good treatment.

- It was pointed out that the GA may well be able to help out where it is problematic to send the large volume of records (that we all have!!) to researchers. Please contact Kathy about this.
- It was agreed that it was too hot EVERYWHERE. 2 members talked about cruising from the US to Norway (where another member “happens” to live!).
- One member has recently had talks with the producers of the Dr Oz TV show. They were interested in her case, and may want to use it.
- Everybody said goodbye.
- ***End Of Story***(as Satchmo says at the end of “High Society”!)
The next chat will be held on Saturday 13th August at 3pm EST.