

Summary of eCD Global Alliance Internet chat On 31 Jun 2012

5 Attendees

- All of the stateside members said that it had been VERY HOT recently. Most were thankful for air-conditioning.
- A member said that the family members were getting a lot of help from a psychologist friend.
- A member had woken with a bad headache. He thought that the AC may have been part of the problem, but later told us that he had a degree of hydrocephalus (water on the brain, causing raised pressure inside the cranium) and that the insertion of a shunt was being considered.
- We were informed that there will be a NORD conference in Washington DC in mid-Oct. Kathy thinks that she will be attending, and that this might be an opportunity for members of the Global Alliance to meet up!
- One member asked whether others had had problems with gum growths. One member had been found to have bony protrusions over her teeth. Both of these members are already under the care of dentists! We wondered whether this might be linked to the ECD.
- Somebody enquired as to whether the NIH and Houston were going to get together. This would make the sharing of data easier. They are not "together" yet.