

Summary of ECD Global Alliance Internet Chat On 26 May 2012

11 Attendees

- A member mentioned the "Narrator" program, which comes with Windows. This program "speaks" out the keys (alpha-numeric keys and the others, eg punctuation marks, Enter, Shift) as you strike them. This is not a speaking keyboard. The speech comes through the PCs sound system. It means that you can hear some of the typos, that you are making, before you look up at the screen. Useful for those of us who can't touch-type. Details of how to access this program will be sent out to those registered with the organization.
- The weather was a point of discussion! Most members were in sweltering heat, but one had the SNOW coming down!!
- Our member who is playing the harp managed to have a lesson today. It is difficult when there are any hand or wrist problems.
- There was a discussion about lawns, backyards, and grass cutting. A member has just managed to get some local kids to mow his yard. He thinks that they either need glasses or a new blade on the mower! Payment is going to be sorted out appropriately. Other members have "people" in to do the grass for them, and are generally happy with this arrangement. One member has a "tame" son who does the work. A member suggested that we should all keep goats or sheep, as they would keep the grass short AND manure it too!
- A member who has recently needed prostate surgery, told us that his recovery was going well.
- One member has already attended the NIH and met Dr Gahl (who featured in the "60 Minutes" Undiagnosed Disease Program shown on TV recently). Dr Gahl came by his room and asked whether it would be OK to bring in some students. The member expected 2 or 3 students, and agreed, and then about 30 people came into the room to hear about ECD.
- Some members had seen the recent "60 Minutes" program and most had enjoyed it. There was a certain amount of disappointment that ECD had not been explicitly featured, but most comments were very positive. The undiagnosed disease program at the NIH, does seem to have a protocol that is amazingly similar to that of the ECD study. It would be very good if we could get some coverage on ECD, and it would be a way to help those still searching for a diagnosis, to find one. Hopefully, we can manage to organise a symposium on

ECD - with researchers, from around the world, coming together to talk about what they know. The NIH program takes only 150 cases a year, and so getting them to take ECD cases is very special.

- A member who is giving a "lesson" at their church next week said that they were a bit nervous. Other members were reassuring.
- A member said that they, and their family, had found it very helpful to have some psychological support through all of their "ECD experience". The father of an ex-pupil had provided the expertise. He had likened the trauma of going through this to post-traumatic stress disorder. Another member, whose brother had been in Vietnam, said that they could understand this. Psychological support does often cost "out-of-pocket" money and for some members this makes it difficult, or even impossible.
- The impending wedding of one member was discussed. Kit and Rich now have their invitations for their commitment ceremony on Oct. 6. Other arrangements are moving along. There has been a "tasting" of the food to be served, music has been arranged, as has a photographer.
- Members were encouraged to try to persuade any people, newly diagnosed with ECD, to register with us. There is "power in numbers".
- A member wore his ECD t-shirt to the dentist yesterday. They had never heard of ECD, pulled it up on the computer, and were impressed with the ECD website. We were told that if anyone doesn't have a t-shirt and would like one, there are still some available. If there is a strong interest, some more can be made.
- A member asked whether anyone has been running into negative comments about the help that they receive? The member had become very aware of negative attitudes, towards anyone who's getting assistance. Some people think that we should be getting nothing at all. This had been suggested by a person who is in a good position. The member guesses that she thinks that she worked to get where she is, and it's too bad if others can't/"won't".
- Members were asked whether any one has had skin cancers. A member has just had some melanomas taken off his face, and a skin cancer removed from his arm. He had a large squamous cell cancer removed from his arm a couple of years ago. Unfortunately, he isn't sure, at the moment, what was removed this year. The question was asked, whether the dermatologist said anything about the melanomas, and any follow up treatment? Did the treating doctor have anything to say about the skin cancers and the use of Gleevec? The member does not believe the treating doctor has been notified yet, but will do so.

- One member said that they had red blotches, and had more than twenty biopsies of the skin, over the years, but nothing cancerous was ever found. Another member said that skin cancer ran in his family, but that he had seen the dermatologist three times, and was now no longer seeing him on a regular basis. Another ECD patient, who had ECD before the Alliance was formed, had a number of skin cancers - basal cell and squamous.