

Summary of ECD Global Alliance chat held on Saturday 5th December 2009

10 Present

- The tee shirt project is progressing, although there has been a delay due to some personal priorities of the individual who is doing this.
- A patient described how they have been suffering from angina recently. They are due to go for tests next week.
- Issues regarding sight were discussed. One member has a relative who was born with Nystagmus (constant eye movements) and has a problem with the pituitary gland. They have problems with night driving and cannot read the big 'E' on the eye chart. Another member described how their relative lost their sight because of tumours surrounding the optic nerves.
- A Dr. Stacey. Pineles is due to present a paper on an ECD patient in Arizona in March.
- A patient on the chat described his problems with dizziness.
- One patient taking Gleevec has been suffering from stomach problems. It has been suggested that they take half the dose twice a day, in an attempt to eliminate the problem.
- The difficulties experienced by caregivers were discussed. It was agreed by all that it is very difficult not to be able to help or change the suffering of someone you love.
- One patient who has a skin rash reported that the doctors were unclear as to whether this was related to ECD. There are several cases of skin rashes reported in the ECD literature.