

Summary of ECD Global Alliance Internet Chat 05 May 2012

8 Attendees

- One member has been exercising, and has managed 5 days at the gym! (This can't have been full days, it must have been in sessions!) But the interferon treatment does reduce the member's energy levels. The present interferon dose is 50 micrograms. Work is very busy, the days fly by; but there is too much sitting, which causes stiffening up of the legs.
- It was said that it was important to gauge your energy levels, and not to overdo things. One ECD sufferer overdid doing yard work a couple of weeks ago, and ended up unable to go to work for 2 days.
- A member has been getting on with wood turning, while another has been making bluebird houses.
- A member had been at a Fish Cookery course all day, and was sleeping it off! His wife came on to the Chat.
- A member, who has been having back problems, thinks that the back is getting better, but there have been belly problems recently, and ECD seems to make these hurt more.
- The NIH study is still going on. They begin seeing patients at the end of the summer. Dr. Estrada-Veras remains in contact with the organization and has seen ECD patients in area hospitals recently.
- A member was baking cookies during the Chat! Due to leg swelling, stronger compression garments have been ordered.
- A member is looking into a Greek Island holiday this year (they have enjoyed these before). Naxos is a favourite; a flight into Santorini, then a 3hour ferry trip!!
- A member who has started harp lessons, has had to skip today's, but is going to try for next week.
- We were told that the 122nd patient has gone onto the register. Members of the organization have been in touch with other patients who are known to have been diagnosed recently, but have not yet registered with the organization. We hope all patients will register with the organization.
- It is hoped to do some more with the organization website, when possible. Some of the research doctors have suggested it would be helpful to add more information about diabetes insipidus, and about exophthalmos (bulging eyes). They believe that this might help some people who are still searching for a diagnosis.
- An enquiry was made respecting a member who has not been on the chat for a while. No-one had had any recent contact.

- Someone called kw came on after the Chat with some questions. kw does not have ECD, but was “trying to bring light to my medical students”, and asked what we could tell about the disease. The ECD Global Alliance site was suggested as a source for information.