

## Summary of ECD Global Alliance chat held on Saturday 9th May 2009

7 Present:

- Two new members were welcomed to the group and the other members introduced themselves. (If you are new to the chat, it can be confusing at first to know what to do, but it is very easy. You just need to type what you would normally say, just as in a conversation. You can be as talkative or quiet as suits your personality).
- One member was using neurontin for leg pain. Another member described how this had affected balance adversely and they had used tegretol as an alternative.
- One member asked the question 'Do people suffer more from leg pain when it rains?' Three members said that they did, one member suggested this may be due to a change in barometric pressure as well as the rain. Various suggestions to help ease the pain were suggested including sitting with raised legs and using a hot pack.
- The benefits of exercise were discussed. Within the group members capacity for exercise differs a lot but it was agreed that it is beneficial to do whatever you can.
- Two members described how they had undergone 'cardiac windowing', a procedure whereby a small hole is made in the pericardium to let out the fluid.
- 43 patients are now registered with the ECD Global Alliance.
- Fatty deposits around the eyes- one member described how they had had fatty deposits under the eyes, another described small eruptions in eyes by the lower lid, another had deposits on both upper and lower lids.
- Members were encouraged to consider participation in Dr. Vaglio's study. The hope is that by reviewing records it will be possible to gain some insight into which treatments seem to work best for specific sites. The more people who participate, the better the findings are likely to be.