

Summary of ECD Global Alliance chat held on Saturday 13th August 2011

7 Present:

- A member described his schedule of hospital trips. These were now down to once every 3 months, (and blood tests at the local doctor on the months in-between). They had been weekly, then monthly. He had not enjoyed the 2 hour waits in the hospital clinic!
- A discussion on the merits of Paul Anka occurred.
- The husband of a sufferer, who has been in hospital for a long time, said that she should be home soon, but she is still feeling weak.
- Another participant, whose son has ECD said that he had recently gone to have his urinary stent changed after one year, but it was OK, so it was left for now. Unfortunately, he is not feeling good today.
- A US member who has been in hospital for a while doesn't find exercising very easy.
- Another patient is getting back on track with exercising. She is lifting weights, and doing "spinning" classes. She said that she couldn't fall off the bike, because she wears "spinning shoes" that clip into place.
- One member said that the sufferer had fractured her hip, he, the carer, had been diagnosed with arthritis of the hip, and their son had needed hip surgery.
- Another member who has been in hospital for months is scheduled to come home this week. Her house has been further adapted. A hospital bed is due soon. A suitable car for transport has been ordered. Her husband, and carer, is very much looking forward to her return home.
- Someone asked who was planning to go to Bethesda. 2 patients thought that it was too far, although one European member will probably be going. 2 US members also said that they would try to go.

- Cladribine therapy was discussed. A member who had had this treatment fairly recently described his regime. A series of daily subcutaneous (just under the skin) Injections on 5 consecutive days, then 3 weeks off treatment. Then repeat for 6 months. There were no unpleasant side effects. CT-PET scans initially showed improvement, although this wasn't sustained.
- Another patient had Cladribine given through a Port-a-cath. He didn't like this. His appetite was reduced and he lost 50lbs.
- The next ECD chat meeting will be on the 20th August, at 1500 EST. You are all welcome.