

## Summary Of ECD Global Alliance Online Chat 09 Feb 2013

### 11 Attendees

- A new member came on before the Chat. The member's mother had been diagnosed with ECD, and was currently bed-bound and mainly asleep. The member asked whether anyone else had been in this condition, and said that they were unsure what to expect.
- Another new member came on, diagnosed in August 2012. This member has knee and elbow pain and sometimes feels very tired. An 18 day spell of vertigo has occurred, and the regular doctor suggested seeing a neurologist, but the member did not do this. The member has been told that the ECD is affecting the cerebellum and the pons. Many members said that they also had balance problems. One member said that it was like "being drunk". Another had been advised to take early retirement because of unsteadiness. This type of difficulty with balance is called ataxia. When there is the sensation of uncontrollable spinning (giddiness) it is called vertigo.  
(See article about balance problems on the ECD-GA website:  
[http://www.erdheim-chester.org/DataFiles/PresentationsAndArticles/Balance\\_Issues\\_by\\_Simon.pdf](http://www.erdheim-chester.org/DataFiles/PresentationsAndArticles/Balance_Issues_by_Simon.pdf))  
In the UK, the Ataxia UK charity has a tee-shirt with "I'm not drunk. I have ataxia" written on the back!
- A member has just one more treatment, in his chemotherapy course with 2CDA (aka cladribine).
- We were asked whether starting chemo had been difficult. A member, who has just started chemo, said that 2 treatments had gone well, although the white blood cell count went down. Hopefully, this will be just a "one time thing". The member feels really good after chemo, with more energy. Another had had 2CDA, but as an injection under the skin, given each day for 5 days, then a month off. This was for 6 months.
- Another had tried many, different chemotherapies (High dose (14gram) Methotrexate, Cytarabine, Interferon Alfa, and then Cladribine/2CDA). Dexamethasone (steroid) had also been used, all the time. The chemo had been a nuisance, rather than really difficult. There were none of the nasty side effects, like bad nausea, but, unfortunately, none of the chemo, except the very first dose, had any positive benefit.

- A member, who has recently started kineret, is having less pain, but wants to avoid needing chemo, if possible. We were reminded that interferon treatment often makes people feel exhausted.
- And, finally on this topic, a member said that “Chemo is not bad, you get to meet people that are in a lot worse shape than you.”
- A member came on, after we had started, and apologised for arriving late. The reason for this was that they had been for a bike ride! With their dogs in trailers, on the back, they had been on a short trip to visit grandparents. It was said that you were never “late” for a Chat, and many of us would thoroughly enjoy a bike ride, if we could stay balanced!
- We “discussed” the subject of “nail” treatments. A member wanted “nice nails”, to go to the NIH with. A member, who has already been to NIH, said that they don’t do anything to your fingers, and that it was good to have “nice nails”. It was felt that, it was safe to have false nails etc. One member had been advised not to have the cuticles trimmed.
- Sadly, we were told that one member’s “little life saver” had died yesterday. The member’s Yorkshire terrier, Curry, had had pneumonia brought on by a stroke.
- Our member, who is a deacon, had to go as Sunday was “ramping up and I’m to be deacon at Mass”.
- A member came on after we had all finished, and will try to be earlier next week.