

ECD Global Alliance Internet Chat Summary 12 November 2011

6 Attendees

- A member who has just been to Bethesda had posted a message that the stay had been fantastic and a full summary would be sent soon. (Summary has been sent already.)
- Someone whose husband has been diagnosed with ECD, had left a post with some queries. She asked about the length of time that members had suffered from ECD, whether we had it in our bones, and what our current treatments were.
- It was said that lesions in all the leg bones are common, also behind the eyes, around the renal arteries, and in the brainstem, pons, and cerebellum.
- One member had had the diagnosis of ECD for 6 years. There were bony lesions, cerebellar lesions, around the aorta and around the heart, and in the lungs. Methotrexate 40mg once a week is the treatment at present.
- Another member had had it for 4 years with lesions in the pituitary gland, carotid arteries, optic nerves, leg bones from the knees down, and peritoneal (= abdominal) aorta. That member had had radiation treatment and interferon injections.
- A further member had had lesions affecting his eyes, lungs, and legs. Cardiac tamponade (a condition where fluid builds up in the sac that is around the heart; this causes pressure on the heart, and it isn't able to pump properly; it is treated by cutting "windows" in the sac so that the fluid can escape, and pressure doesn't build up) needed treating too. Treatment was with 2cda and surgery to make the "windows".
- A member who wants to sell a property in Florida, hasn't been successful yet. A move is needed because dogs aren't allowed on the site, and the member has one. The member also achieves his 52nd wedding anniversary on 13 November. Congratulations from all of us!
- A member has a date to fly to Bethesda. Shopping trips are being planned!
- The trip to Bethesda is going to involve time with the physiotherapist. Hopefully this will address some of the balance issues. It will be combined with the results of scans to assess how well the cerebellum is working.
- We were asked by one member whether any of us had sinus issues. 2 of us have been found to have ECD in our sinuses.

- A member who had not been able to Chat for a while came on. There had been a few rough weeks, but things were going better now. Much more energy. The next couple of months are very busy, but then a trip to Bethesda is likely.
- The partner of one member has been working on sea aquaria, a long term interest. The partner who is a sufferer just needs to contact NIH for a date to go. It will probably not be until March 2012.