

Summary of ECD-Global Alliance Internet Chat 02 Feb 2013

8 Attendees

- A new member, from Cincinnati, came on and told us that, they had been diagnosed with ECD in August 2012. Diabetes Insipidus has been present for seven years, but other symptoms appeared over the past two years. This was the first time of joining the chat, but the member reads the notes, weekly. He asked what tests had been requested for members, by cardiologists. One member had had a cardiac MRI scan. This had not been an enjoyable experience!
- Another member said that they had also had diabetes insipidus, in the early nineteen-eighties, and ECD was not diagnosed until 2005.
- Weather conditions were compared. A lot of the US members had snow, although it had melted in the UK.
- The new member told us that Interferon had been started, weekly, six weeks ago. An infusion of Zometa (zoledronic acid) had been given this week and had caused a bad reaction.
- A member asked whether anyone was having extremely sharp pain, in any of their joints. And if so, what did they do to help with this pain? This member takes Interferon, weekly, and Zometa every 3 weeks. It has helped, slightly, with the pain. It makes the member feel worse, on that day, but then the pain is reduced for almost 3 weeks. Zometa was used for 2-3 months before a reduction in bone pain was noticed. Pain is increased just after the injection.
- We were asked, whether we had attended the NIH study. Three members, on the chat, had already been. They had, all, found it very useful, but it is a “hard week” of testing, and seeing many different specialists.
- A member, who had recently started a course of chemotherapy, only has 2 more weeks to go.

- We discussed how rare it is, to actually meet another ECD patient. Three members had never met another patient!
- We mentioned the symptoms that had first started us on the ECD merry-go-round. Lower leg and knee pain was a common first symptom, and then this was followed by abnormal X-ray findings.
- One member had had problems with thirst, fatigue, and light-headedness. Two attempts are often needed to get up the steps, without falling over. Another had developed double vision, and slight “wobbliness”, and an eye doctor had got a scan, which showed swellings behind the eyeballs.
- Two members see eye specialists, and another sees a neuro-ophthalmologist.
- All of us said that our family care-givers did a great job, and we were all grateful to them. We also agreed that they all have a very heavy burden to carry. “Surprise visits” were mentioned. One member doesn’t seem to get any, another lives far away enough (from both sets of in-laws), that “surprise visits” can’t happen (and likes it that way!). Finally, on this subject, a member told us that the grand-parents do drop by, sometimes.
- A member reminded us about his hopes to produce a book of “inspirational” stories, to help others, going through difficult times, due to health problems.