

ECD Global Alliance Internet Chat Summary 04 Feb 2012

Attendees: 12

- A member has just had another PET scan. Not a very enjoyable process. And a 10-12 week wait for the next appointment with the doctor. Although the member thinks that the hospital will make contact earlier if necessary.
- A member, who has had longstanding back problems, has started having pain-killing injections, and these have helped a lot. He is now able to walk with just a cane.
- A member had heard, on the radio, that there was a new ruling in Norway that employees only get 8min "bathroom time" a day! Our Norwegian member had not heard about this.
- A member has just "celebrated" the one year anniversary of obtaining an "official" diagnosis of ECD, after 6 years searching! The hunt for a new job has not been successful yet. Good luck from us all. Despite tiredness from interferon, continued use was advised. One member had had reduction in fibrosis behind his eyes, but only after 8 years!
- Another member's son had taken 10 years to get a diagnosis.
- A member has started Crestor for raised cholesterol, and had fosinopril, for raised blood pressure, doubled in dose. The raised cholesterol, and blood pressure, are thought to be side-effects of Kineret, but this is a small price to pay, compared to the side-effects of interferon.
- A member has received one set of his medical records back. His wood turning efforts are continuing.
- A member who recently lost his wife to ECD, is, naturally, still lonely. He has been having some difficulty with a bony spur on his foot, which affects his ability to walk.
- The woman who has been doing a film on Histiocytosis has finished shooting, and has been sent some information specifically about ECD.
- Dr Kurzrock has e-mailed Kathy, and said that they are now doing some genetic-type research on ECD at M.D. Anderson.
- There was a discussion about some current cinematic "blockbusters". Iron Lady, Warhorse, and Hugo in 3D. Hugo was praised, Iron Lady was said to concentrate too much on the difficult periods of the main character's life, and

Warhorse was found upsetting by those who don't like to see animals getting hurt. Members preferred to see something uplifting; one member admitted getting upset just by watching baking competitions!

- A member has an upcoming visit from her sister, who she has not seen for years! She uses a loom for weaving, but this needed repairing recently. It is new to her, but actually 30 years old! The husband of a nearby friend can fix things, but she managed by herself this time.
- Our "Soon To Be Wed" member had a good Drs visit. With one more "good" check up, she will be moved from 6 monthly to annual visits! She is just taking a low dose of DDAVP for DI.
- A website for you all (in the US) if you wish to keep up with Rare Disease Legislative bills and such: <http://www.rarediseaselegislativeadvocates.org/>. This organization is doing a Lobby Day with Representatives on 28 Feb if anyone is interested. This is the link:
http://www.congressplus.com/events/index.cfm?action=Event_Page&eventcode=sEigsf&bypass=true.
- Some of the members are meeting in the DC area for Rare Disease Day. We will be attending the NIH conference on 29 Feb. If others can make it, we hope that they will join us.
- There has been a recent ECD article that came out from Dr. Haroche's team. It looks at 24 patients on interferon and shows the results. Basically it says what we hear here...interferon seems to help the majority but it takes awhile.
- The link to the abstract can be found here:
<http://www.ncbi.nlm.nih.gov/pubmed/22300602>.
- After we had all finished, a member came online that had been unable to link up before. Computer problems have become a real bugbear. We were all wished a good week.