

Summary of ECD Global Alliance Internet Chat on 02 June 2012

7 Attendees

- A new Chatter came on, having been diagnosed just 4 months ago, and hoping to get some more information and support. The new Chatter lives in Northern California, was diagnosed at UC Davis Hospital in Sacramento, and is using interferon at present. All diagnosed patients and their loved ones are encouraged to register with the ECD Global Alliance by simply emailing support@erdheim-chester.org.
- Some of the other members then gave short accounts of their stories.
 1. A 73 year old was diagnosed in 2003 after 10 years of investigations. Had 3 months of Gleevec treatment in 2009, and has been stable since.
 2. A 50 year old, diagnosed in 2005, had to retire from work as a physician, at age 45. Takes methotrexate tablets, 40milligrams, once a week. Stable for the last 2 years.
 3. A member, whose husband died after a long undiagnosed illness that turned out to have been ECD.
- Discussion showed that we had all had different symptoms, there was a long time before diagnosis, we all had difficulty finding doctors who had even heard of ECD, and few of us have ever met another patient, except “across the internet”! At the moment there is no Global Alliance Facebook page. However, anyone who would like to volunteer to create and maintain a page is encouraged to email support@erdheim-chester.org.
- A member is having botox injections, every 3 months, in an attempt to reduce spasm in the leg muscles. This treatment has not been very effective as yet, and the doctors are gradually increasing the dose used.
- Our harpist member was in the “off” week from a lesson. Practice is limited, because after 10 minutes, the back becomes painful.
- We were told if an ECD patient has a biopsy scheduled, then, it would be helpful, if they get in touch with Dr. Estrada-Veras at the NIH, or Dr. Allen at Texas Children’s, prior to the biopsy. Both of the studies being done by these doctors are looking for tissue from ECD lesions. If a section of the biopsy could be sent to them, it will aid them in their research greatly. However, coordination is vital BEFORE the biopsy is taken, so that the sample is preserved correctly.
- Towards the end of the Chat a member started to complain of having pain after an injection. By all accounts, this had been given by a “roving” nurse let loose with a hypodermic needle and syringe! The patient reports he is doing okay now.