

Summary of ECD Global Alliance chat held on Saturday 7th August 2010

9 Present

- A member who was new to the chat sessions was welcomed.
- A patient described, how, when they lay on their side, they lose their voice for a while. This is thought to be due to granulomas pressing on the lungs.
- The NIH researcher is continuing on the path to get the ECD study started. Dr. Vaglio is also making good progress in working towards starting a study on ECD.
- Members were given a question to think about, possibly for discussion next week. It is 'Often times we are asked for our input on certain subjects such as fundraising, yet we tend to shy away from responding .What would help each of you to bring you to a place where you could be more interactive and become more involved? Even a small idea can become a great idea. Think about what your community does for fundraising'.
- The fundraiser organized by several members last weekend raised \$2000-3000.
- Several patients represented on the chat had experienced eye involvement. For two of the patients, it was eye specialists who had diagnosed ECD. One patient reported that treatment with interferon had helped stabilize their eyes. One patient had surgery to remove tumours behind the eyes, and had undergone surgery on the eyes 4 times. Tumours behind the eyes were preventing the patient from moving their eyes side to side.
- Several patients discussed that they were diagnosed due to lung involvement. One patient thought there had been an improvement in their lungs due to treatment with Gleevec.
- One patient has suffered from diabetes for the last five years, thought to have been brought on by treatment with prednisolone, which proved ineffective in treating ECD. This patient may shortly have to start on insulin. A question was asked about how to avoid weight gain when on insulin (injections). This patient currently takes imuran and tamoxifen which seems to be keeping the disease stable.
- The next chat will be held on Saturday 14th August 2010 at 3pm EST.