

Summary of ECD Global Alliance chat held on Saturday 27th June 2009

9 Present

- One patient has recently had a consultation with Dr Kurzrock in Houston. The drug Gleevec has been suggested, which has been used in the treatment of patients with leukemia. The drug was approved by the FDA in 2001. More information may be obtained from the official Gleevec website.

(Note: At least one medical journal article appears on the use of this treatment. See: [Imatinib mesylate for platelet-derived growth factor receptor-beta-positive Erdheim-Chester histiocytosis](#), published 2008. For more information about this article, or what it may mean in your particular case, you should contact your treating doctor.)

- The ECD Global Alliance represents 46 patients at present.
- The question was raised about how many patients have submitted their stories to the 'Mystery Diagnosis' TV team. (Please see Kathy's e-mail of 14 June. 'Mystery Diagnosis is a TV program that aims to raise awareness of rare diseases. They are currently looking for new stories, one of which may be centered around ECD). One member had spoken to a representative from the program who had said that there is no guarantee that they will do the show unless they get a good story. A decision is planned for the end of the week. The TV team is specifically looking for a story about misdiagnosis and the journey/frustration of finding the correct diagnosis. Members were encouraged to submit their stories soon if they are interested in contributing to the program.
- There was a request for articles for the next newsletter. Ideas for articles may include how you were diagnosed, the frustrations of dealing with the disease, the good things that may come from the journey etc. Articles should be sent to 'stanceforlance@hotmail.com'.
- Much of the chat was spent chatting about things happening in the participants' lives, and various hobbies and interests that people enjoyed.