

## Summary of ECD Global Alliance chat held on Saturday 14<sup>th</sup> March 2009

### 10 Present

- One member has written an excellent article for a local hospital newsletter on Rare Disease Day and the way ECD has affected their family. This article has recently been e- mailed to members.
- One member has made a recent long distance visit to Dr Kurzrock.
- One member who has a new diagnosis of ECD joined the chat for the first time and was welcomed to the group. After introductions from other members they described their experience with ECD, mainly concerning lung involvement, causing tiredness and shortness of breath.
- The side effects of interferon were discussed. One member described how the side effects of this drug (usually tiredness and flu like symptoms) had reduced after about a year on the drug. One other member had also had this experience. Although the side effects were still present for both patients the severity of the symptoms were reduced.
- The merits (or otherwise) of interferon vs chemotherapy were briefly discussed. It was concluded that every patient has a completely individual response to each drug and treatment regime.
- One member visited Paris recently to see Dr Haroche and undergo various investigations as part of Dr. Haroche's study. The investigations included a head MRI, cardiac MRI, high resolution chest CT, pulmonary function test and extensive blood testing. The results should be available in the next 2-3 weeks. Dr Haroche has seen approximately 40 patients with ECD.