

## Summary of ECD Global Alliance chat held on Saturday 18<sup>th</sup> July 2009

12 Present

- Two members who had not joined the chat previously were welcomed. Both commented that they found the information shared by other members extremely helpful.
- There was a discussion regarding eye involvement in ECD. While this is common not every ECD patient will have it. One patient has recently developed ECD masses in the eye orbits, having had other symptoms for some time. A biopsy has been suggested. One other patient on the chat had required a biopsy behind one eye. The risk in this procedure for this patient was that the ECD masses surrounded the optic nerve and there was a risk of damage to the nerve in the course of the procedure. For another patient who had experienced eye involvement, the oncologist had declined to do an orbital biopsy as he was of the opinion that it would add little information and was a painful procedure. One patient thought that interferon has prevented eye problems from getting worse.
- Good news – one patient had a recent CT scan which showed no changes, also, the patient's blood results are within normal range for the first time in 18 months.
- One patient is in the third week of taking Gleevec. They feel their energy levels have improved but their eyes are worse.
- Different therapy regimens were discussed. One patient tried various therapies before an effective drug was found. Prednisone was of no use and had significant side effects; radiation therapy resulted in a slight reduction in masses but these grew again as soon as the therapy was stopped; imuran is now proving effective in conjunction with Tamoxifen. Another member described how three treatments had been tried, prednisone, 2 CdA (cladribine) and interferon. Each brought progressive results and the patient is stable now. Members/patients on the chats often describe how various treatments have been tried before an effective treatment was found and this seems to be a common experience.
- A new member described how open heart surgery in December 2008 had led to a diagnosis of ECD. They are due to meet Dr Kurzrock in Houston shortly. Their symptoms include diabetes insipidus, bone pain, pituitary involvement, heart valve involvement and retroperitoneal fibrosis.
- There was a general discussion about how, in several cases, people thought that their previous medical issues had been the first indicator that they had ECD, some considerable time before formal diagnosis.
- Depression is a recognized side effect of interferon, although depression may also be a result of having to cope with long term illness!
- There was a question regarding the progress of the research study being proposed by Dr Vaglio in Italy. Dr. Vaglio is not quite ready to commence work as he still needs to obtain some approvals. What members could usefully do is start gathering relevant medical records so that they may be sent to Dr Vaglio promptly when he is ready to commence work on comparing different cases from around the world.

- One member said that the group had given them the hope and knowledge that people with ECD can live with the disease and have a decent life. Other members expressed how valuable they found the support from the group.