

## Summary of ECD Global Alliance chat held on Saturday 22nd August 2009

8 Present:

- One patient has recently suffered from seeing shadows whilst driving. Another patient had experienced 'fluttering in the periphery' when their eyes were first affected.
- For two patients, an MRI scan of the head had provided confirmation of growths behind the eyes. One patient had undergone a biopsy of the growth.
- Jeri, Ralph and Kathy are finalizing the paperwork for the ECD Global Alliance to become a non-profit organization. Once this is approved by the government agencies, the group will be able to do fundraising for possible research/support work.
- One patient has recently had surgery to remove a growth from their jaw. It seems likely that this is ECD. If so, the patient will need to wait for any residual infection to clear before starting treatment.
- There was a brief discussion about the management of energy levels, with people needing to space out activities and choose the best time for various activities.
- Two patients described how they experienced light headedness and dizziness.
- For one patient who is due to start treatment shortly, they commented that their doctors first considered interferon, then steroids and are now considering cladribine. A number of patients in the group have been treated with this drug, using different treatment regimens.
- A patient who stopped working due to the disease is fighting to get disability. Another patient said it had taken two years before this was resolved, but they had received back payments.
- A member described how they found taking various supplements helpful; it is important to tell your doctors what (if any) supplements you are taking as these may interact with prescription medicines.
- The next chat will be on Saturday 29<sup>th</sup> August at 3pm Eastern time.