

## Summary of ECD Global Alliance chat held on Saturday 12<sup>th</sup> June 2010

### 7 Present

- One patient reported that their insurance company won't cover any drugs for the treatment of ECD. The patient's government has declined to provide any funding for experimental treatment. The patient is appealing to the drug companies to provide an off label prescription..
- A patient has recently been experiencing what feels like an electric shock, 'like touching an electric fence'. Another patient mentioned that they had also experienced these feelings.
- A patient joined the chat who has not been able, (due to work commitments) to attend the chat for a while. They have been on interferon for over a year now; they have had leg pains and have suffered a heart attack.
- The question for this week was 'If you or your loved one could be pain free or disease free for one day/one week what would you do differently to enhance your life and give you pleasure? Remember you have unlimited funds to do whatever you want' Members on the chat discussed how they would spend time with their loved ones doing things they enjoyed e.g. cooking, going out for meals, sightseeing and travel etc.
- A question was raised as to whether patients took cladribine and interferon at the same time. Two patients had received both of these treatments but not at the same time.
- One member described how their family member with ECD had been greatly helped by sessions with a psychologist. Another member mentioned that there are psychologists who specialize in dealing with patients with chronic pain and medical issues. Another patient described how they found volunteering at a local centre for patients with neurological problems helped them stay positive.
- There was a brief discussion on the subject of fundraising; some restaurants and restaurant chains will arrange fundraising/benefit evenings for various charities.
- The next chat will be held on Saturday 19<sup>th</sup> June at 3PM EST.