

## Summary of 1-18-09 ECD Chat

**Chat Date:**

1/18/09

**Time:**

3 pm Eastern time

### 6 Attendees

#### Summary:

- There was a fair amount of general conversation about activities different participants have been doing. One participant had a recent birthday and everyone wishes her a happy birthday. There was talk about different foods and baking which made most hungry.
- One patient is planning his trip to see Dr. Haroche in March and another is working on getting paperwork to Dr. Arceci. Both patients feel they getting good treatment from their current doctors, but are interested in what those who have treated multiple cases might offer.
- We heard one patient is now volunteering at a local center that sees patients with nervous system issues. He is helping people understand how they might be able to use inexpensive equipment to help them live life to the fullest possible. Way to go!
- There was a discussion about sight issues related to ECD. One participant mentioned that they had talked to a family member of a patient who had lost their sight to ECD. Another patient remembers corresponding with a patient in Europe who had surgical procedure and was then able to see again. One patient finds her sight is changing rapidly and must change her contact prescription on what seems like a weekly basis. Still another patient has found his eye sight continues to improve now that he has less stress being retired and has been on 2-CdA treatment. One patient has had no eye or sight issues at all. Sight issues are something most seem concerned about.
- A small discussion was held about the cost issues of medicines. In the US one patient is able to get their interferon using the Patient Assistance Program with the pharmaceutical company and their other medicines using the Walmart plan of \$4 plan for generic drugs. Another patient feels she had good drug insurance yet still had to pay out of pocket expenses in excess of \$2000 in 2008. In the UK one is able to obtain free medication if you qualify based on various criteria, one of which is if you suffer from seizures. The downside of this benefit is paying 40% income tax on incomes over 35,000 pounds/year<sup>(1)</sup>.
- Participants discussed how the temperature impacts ECD patients. Some patients used to be comfortable with a wider range of temperatures, but now find they are comfortable only in a narrow band of temperatures. A couple

patients find their balance and/or speech is worse during hot weather. Another patient seems to sweat excessively in hot weather. Most seem to prefer temperatures on the cooler side since becoming ill.

- Seems almost all ECD patients find they are tired and sleepy all the time. One patient is scheduled for a sleep apnea test in the next few weeks to see if he is suffering from that. For more about sleep apnea see – [http://en.wikipedia.org/wiki/Sleep\\_apnea](http://en.wikipedia.org/wiki/Sleep_apnea). Some of the sleep apnea symptoms could also be due to ECD or the medicines an ECD patient might take. One patient is tired when he awakes, another feels better upon waking, but tires very easily after exertion.

<sup>(1)</sup>UK NHS Medicine Benefits (from our UK citizens):

1. All in-patient hospital treatment on the NHS is free to everyone.
2. On the NHS all medicines for people of retirement age (65 for men, and 60 for women), children (under 16), and those in full-time education, are free..
3. Certain medical conditions allow you to have ALL your medicines free. These illnesses include diabetes (on treatment, not diet alone), under active thyroid (needing thyroxine), epilepsy and if you have a stoma needing bags of some sort.
4. Certain "Benefits" bring free medicines too. This is a means-tested qualification for your medicines.
5. However if you buy an annual "ticket", which is about £100, then you do not have to pay anything more that year, however much medicine you need!