

Summary of ECD Global Alliance Internet Chat 27th July 2013

7 Attendees

- The member that has been at an MS rehabilitation centre, has now been at home for two weeks, and is back at work, work, work! She enjoyed being able to do so much exercise, and has been started on a new medicine (fampyra) which, she thinks, is already helping with walking and balance. This medicine it is quite new, and is called the "walking pill". The member has found that it makes her feel a little less stiff, and makes her walking a little better. People at work have commented that she walks better now. It is a very expensive medicine though. She has e-mailed Dr Estrada-Veras, at NIH, about it. A member commented that ECD patients should try, when possible and with medical supervision, drugs that are used for other, more common conditions that have some similarities with ECD. Big Pharma will be much more interested, as it's all down to \$\$\$\$ in the end!!!
- The member, who has been at the MS centre, is still waiting for BRAF results. (See <http://www.clinicaltrials.gov/ct2/show/NCT01524978?term=roche+braf&rank=5> for information about a clinical trial opened for BRAF-positive ECD patients in the US and Europe.)
- A member had asked whether it was beneficial to go to the NIH in Bethesda. A member, who has, already, been twice, said that she would absolutely recommend going to the NIH. She "can't wait" until a year has gone, and she can ask whether she can go again! There are lots of doctors working well together, and they actually know what they are talking about. You get a full check of your entire body, starting with blood and urine tests. Then there are MRIs, PET scans, heart and lung tests, and tests of other organs that you might be having problems with. The visits had been full of "Busy days at a big hospital!" Another member "couldn't believe how hard I slept when we got back from Bethesda".
- A member whose son has ECD, and has been to the NIH, said that he had tests run from 6:30 am to about 5pm, for 5 days. The NIH paid his, and his wife's, air-fare for the round trip. They were put up in a motel, and his wife could eat in the cafeteria for free. After all the tests and examinations, you will get a written report of all the results. If members are able to travel that far, please e-mail Dr. Estrada at juvianee.estrada-veras@nih.gov. He can give you more detailed information about the study.
- Members discussed whether they will be going to go to San Diego. Two from Europe, and one from the US, said that they wouldn't be able to be there. Others, who are going, said that they were looking forward to meeting each other.
- A member has a "no pets" clause in his lease, although the landlord lets him have one dog. Benji is a "favour", and the landlord hasn't raised the rent in the whole 12 yrs that he

has been there, due to his condition. Recently, his wife told him that a friend from church was bringing their Cocker over to stay for 2 wks, while their sons are getting married in OR. He feels that sitting another dog is deceptive & risky. This member has, recently, had some tests done. These have shown that he is hypothyroid, but the condition of his eyes has, actually, improved!

- A member told us that he was originally from Manchester in the UK. A UK member lives near Bradford, which is only an hour's drive away, from Manchester, but they were never "neighbours"!
- One member told us that she was in Baton Rouge, at Starbucks, while her mom and her mom's friend are at an Antiques Roadshow! There is a drawing to get tickets to the show, and her mom and her friend only got two, so she is the chauffeur this week! She doesn't drink coffee, being a tea girl! She told us that Starbucks has good iced tea and, also, good pastries. She was late getting there and hadn't even purchased a cup yet. She was just hi-jacking their wi-fi!
- A member has been having difficulties getting a prescription sorted out. The doctor was supposed to have sent off a prescription, to the suppliers, over 4 weeks ago, but nothing has happened. The member told us that he was "in the market for a new endocrinologist".
- It seems to be likely that many of the docs who are ECD-knowledgeable (Haroche, Estrada-Veras, Hyman, Vaglio, Dagna, etc.) are planning to be at the Patient Gathering in San Diego! And it looks like there will be representatives from Israel, Ireland, Australia and perhaps other countries. To register see -
<http://events.r20.constantcontact.com/register/event?oeidk=a07e73ss7vic308c2f1&llr=vxnuk4lab>