

## Summary of ECD Global Alliance Internet Chat

7<sup>th</sup>Dec2013

### 11 Attendees

- One member was on "parole". He had been "released" overnight, from hospital, where he had had a minor procedure under general anaesthetic on the previous day. He had to "report for duty" at the hospital again, on the next day. He has a three day course of intravenous antibiotics to finish. This is for a urine infection. Other members said that urine infections were "real pests".
- A member told us that he had met his "very first ECD patient" this week. 'He lives about an hour's drive away and came over for coffee and lunch He hasn't any neurological problems and still drives a car. His main problem is with his chest. His breathing capacity has fallen a lot. The member "suggested" to him, that he might like to start blowing the trumpet. But he didn't seem very keen on this idea!
- A member has now been on vemurafenib for 6 days. She doesn't feel a difference yet, but is tolerating the medicine well, with no side effects. She has started on a lower dose (2 tablets in the morning, and 2 at night) than that used in melanoma patients. The doctors don't really know how long before she should expect some effects. She is not expecting any improvement until her next check up with them, in one month. She is taking a break from work, and will be on sick leave for the rest of the year, so "now I can focus on myself". She lives in Norway, and said that she won't have to worry about the sun, because it is "rainy rainy rainy". In the previous few days they have had a storm, with strong winds, and snow.
- A member is getting very frustrated with his PC. When it gets taken for repair, it comes back with more problems!
- For one member, the cold weather has been compounded by broken water lines in the house, AND his heater going out, on the same day. So he has had no heat all week, and was without hot water for two days. It cost \$3400.00 to fix the water, and it will be a further \$2900.00 when they finish the heater. Things have been very bad for this member. The report, a 5 page document, from his recent biopsy has gone astray.

He had gone, the previous day, for an MRI scan. The orders had been messed up, and he had to sit all day to get half of it done, and he has to go back to get worked in for the rest.

- On the subject of scans, a member has recently had a PET scan. The appointment was at 07:35. The camera stopped working before she got started. That was fixed by 12:00; and she was only done with the scanning by 14:30!
- A member was asked about his recent "round the world" trip, which included the ECD conference in San Diego. He said that the trip had been "absolutely wonderful". He had met with many of the ECD "family", both in the US and in the UK. He had particularly enjoyed sitting chatting. And the longest delay in travel, of the whole trip, was at Heathrow, leaving for home (Australia), when the SwissAir flight was delayed by 60 minutes, due to snow & ice in Zurich. He got home safely, but had to take it easy for a few days. He only worked for 6 hours a day in the parish.
- A member enquired whether the NIH will help with the cost of biopsies. Nobody knew the answer, and he was advised to ask Dr Estrada Veras. The member asking about this is scheduled

for a retro-peritoneal biopsy for the B-RAF study. This member has been told to cut his dose of synthroid (a thyroid hormone replacement) in half. He hopes that this will "fix" his vertigo.

- A chatter changed screen name. She is the wife of a man who has ECD. He doesn't speak English, and so she is the "Chatterer", and now it is her name that will appear.
- There is now a list of ECD Care-Givers, for support. RuthAnn is organizing this, if you are interested please contact her. There will be a CareGivers Facebook Page.
- Members on both sides of the Atlantic have had times when they have arrived for appointments, and the hospital has not had them on the list, making the journey pointless. One member tries to call the day before, to make sure that they are on the schedule. This only requires a phone call. Another member will start to do this soon.
- Members talked about their symptoms. Some said that when they are tired their speech, and balance, get worse. Memory problems were also mentioned. Walking was talked about. Use of a cane was recommended, and, for those that can't use a cane, a walking aid can improve things. One member has had to go back to being on crutches. His problem is partly due to biopsies taken from his legs.