

Summary of ECD Global Alliance Internet Chat 04 May 2013

6 Attendees

- The member, who had been on the Chat last week, using a netbook, while staying in a nursing home, is now back in his own home. Today, he had been out for an early tapas meal. The only disappointing element was that it was in Halifax, West Yorkshire, and NOT on a beach in the Mediterranean!
- A member has recently been to the opera for the first time and enjoyed it. Unfortunately, in rural Louisiana there isn't much opportunity for the fan of ballet or opera!
- We were asked whether we had, lately, been to the www.rareconnect.org website. More people are registering and, hopefully, this will become a good site for sharing of information. We were advised to take a look, and that we shouldn't be shy about posting. Others will appreciate the sharing of our knowledge.
- A member has started Low Dose Naltrexone (LDN) therapy, and quit interferon. This has helped the member able stay awake in the evening with more energy, but that's about all so far after 2 weeks.
- A member asked whether the conference in San Diego will be videotaped. It is hoped that this will be possible. The limiting factor will be cost.
- Some members said that they may well not be able to get to San Diego. Kathy asked members to let her know if they need help with planning their trip.
- Three members have had good results from recent physiotherapy (physical therapy) treatments, and have pleased their physiotherapists with their results.
- A member, from California, joined the chat for a second time. They are taking kineret twice a day, the main side effect of which, is fatigue.
- Researchers are finding that about 50% of ECD patients have a BRAF mutation. There is a treatment that is used in melanoma patients, who also, often, have a BRAF mutation. There is a clinical trial (US only at this point) for the BRAF inhibitor. See: <http://www.clinicaltrials.gov/ct2/show/NCT01524978?term=roche+braf&rank=5> .

So far, the BRAF inhibitor has only been used on a very limited number of patients. The three patients followed in the referenced journal article had multisystemic ECD and responded well to treatment. There is still a lot to learn about this, but it is extremely hopeful. Dr. Haroche, in Paris, was the first doctor to try it and report on its use in ECD patients. (See: <http://www.ncbi.nlm.nih.gov/pubmed/23258922> and <http://www.ncbi.nlm.nih.gov/pubmed/23597965>.)

Some members had already been tested for the BRAF mutation, others were having the test done, and others wanted to know how they could get the test performed on themselves. The name of the BRAF inhibitor drug that is currently on the market in the US is - vemurafenib. This drug is VERY expensive.

For interested patients, in the US, that are close to a centre participating in the vemurafenib trial, it is worth looking into whether the trial could help with the drug costs. The down side is, that the monitoring, during the trial, requires the patient to return to the doctor every 3-4 weeks.

- A member asked whether anyone had experience with Clofaradine. It's a drug used in the treatment of lymphoblastic leukaemia. Nobody else had had any experience of this medicine. Some members have had treatment with cladribine (2cda), and this is also a leukaemia drug.
- A member is recovering from bad throat inflammation. Steroids have been prescribed, and things are getting a bit easier. This member was diagnosed with ECD in 2010, is 72, and had been using DDAVP since 1992. Another member, who has improved significantly, now, only uses DDAVP, at a very low dose.
- A European member has been having some difficulties arranging for a biopsy to be sent to the US. This process isn't easy, and local doctors have not felt up to contacting the US doctors by e-mail because they are not confident enough with their English skills.
- It was said that most doctors are leery of jumping on the latest research, if their patient is doing ok on older treatments. On the other hand, it is great news that optional treatments are emerging for when they are needed. As more research is performed, the newer treatments will become tried and tested, and we'll all know better who is likely to benefit from what treatment, and better understand the side effects of all the treatments.
- A member asked whether anyone had had a REALLY dizzy spell, starting at waking, and lasting several hours. The room was spinning hard and fast. This sensation of spinning is what the doctors mean when they say "giddy" or "vertigo". Light-headedness is something different, and can occur if your blood pressure is too low.