

Summary of ECD Global Alliance Internet Chat

23 Nov 2013

16 Attendees

- The large number of people on the Chat, last week, was mentioned. The summaries of the conference meetings were also talked about. They have been sent out, and posted on the web-site.
- One member lives in a state in the US where they “don’t do” Daylight Saving. This made them mistake the start-up time for the Chat, but the member turned up later on!
- The weather was a subject for discussion (as usual). Some members are seeing a lot of rain at the moment. This is worse for those living at high altitudes. Also the dark mornings and evenings were mentioned.
- A member fell twice in the previous week, hurting her neck and her ribs. She is just about to start vemurafenib, which the Norwegian government has agreed to pay for! She is thankful to the docs who made the case for her to have funding. She hopes to start at a low dose, and then to work up. We were told by a patient’s husband that some start very high (1920mg), and some start with low dose (480mg).
- A member, from Australia, broke his journey home, from San Diego, to see friends and relations in the UK. While he was in the UK, he went and stayed, overnight, at the home of another UK member! A new member, who lives further South in the UK, near Sheffield, is planning to come for tea, in the next 2 weeks! They both see the same Doc in Leeds, and she is going for a Doctor’s appointment. Our other member’s last visit, to this clinic, took 5 1/2 hours from door to door. That was a LONG visit at the doctors. And only 5 minutes in the room with the Doc!
- A member in the US is doing well. He worked for 11 hours on Wednesday, with only 1 break. He and his wife are on the coast celebrating their 21 Wedding anniversary.
- Next year’s gathering will be in Bethesda, September 19-20. A UK member, who couldn’t make it this year, hopes to be able to go, as the flight will be much easier, and shorter!
- One member has had a bad week. He is needing to use a wheelchair and said that “all this wheeling around in wheel chair is tough”.

- The BRAF mutation was mentioned. To test for this, a biopsy is taken. Some have the biopsy taken from around their kidney area. It is published that approximately 1/2 of ECD patients are thought to have the factor, although emerging new data is suggesting that more patients may have this mutation. (Editor's note: For this reason, any ECD patient who has previously tested negative for the BRAF mutation is encouraged to be retested at a facility that can do an ultra-sensitive test.)

Those patients having the BRAF mutation can be a part of the new study with Vemurafenib. A member, already on the drug, used to spend most of her day in her recliner or wheel chair. Now she is going out to lunch with friends, and can cook and do dishes. Her world has really opened up since being on the new drug. A member told us that, if she can do dishes now, he is not sure whether he wants to take vemurafenib! He is worried that he will have to start ironing and vaccing up!!! The doing dishes wouldn't be so bad, as he's got a dishwasher/wife! Another member said that he thought that you can sign a waiver before the trial, saying that if you get better, you still don't have to do any additional housework!

A question was raised; "where are these waivers to sign?"

- A member has recently had a biopsy, taken from his leg, to test for the BRAF factor, and hopes to hear about this soon. He has not yet been to the NIH. He doesn't know what he will do, if he is BRAF positive, as there are no trials anywhere near him.

Since the biopsy he has not been able to get around. The sample was taken from his good leg. He thinks that he hurt his other leg with his crutches, and he had a biopsy taken from that side, a couple of months before. His pain medicines are not working, and he can't put any weight on it. He is taking percacet/percocet (this is often spelt in 2 ways; it is a mixture of acetaminophen & oxycodone). Many people use Kineret, and this seems to help with leg pain. Other patients have told us that they have needed something stronger, and have used a Fentanyl patch for pain.

The week before the biopsy, he had started on an anti-inflammatory, which was helping tremendously. But now he is back on it, and it isn't helping. He is going back to his regular Doc, after the holiday, and will mention this. His Doc is in contact with Dr Estrada Veras, at the NIH.

- A member from Israel came on, and told us that his wife, who has ECD, is doing well. They are both glad to be back home after their trip to San Diego!
- A member whose husband has been on chemotherapy for bowel cancer, told us that he is now off the chemo, and is waiting for a "reconnect" operation. She herself has been taking Kineret and Methotrexate. She has been on Low Dose methotrexate for Rheumatoid Arthritis for about 10 years. This "Low Dose" is a lot

less than the "Low Dose" that another member takes for his ECD, but both "Low Doses" are much less than the amount used to treat people who have cancer.

- A member, who was rendered blind by ECD, has been working on getting to the local mall from where she stays. Her blindness is her worst problem. The journey takes an hour and 20 min by bus, and maybe a third of that by car. Her mobility teacher took her parents around with their eyes shut. They had found this "pretty harrowing".
- A member mentioned the blog ("Without A Manual") of a woman in Canada who has written about her experience with ECD. [Editor's note: To see this and other blogs, <http://www.erdheim-chester.org/Blogs.html>.]
- There was some discussion about applying for SSI benefits. It was said that, the thing that had helped most, when a member applied for benefits, was giving the interviewer a list of the 9 or 10 docs, that were involved in his daughters care. The interviewer said that a couple was enough, but he gave the details of ALL of them.
- After the Chat had finished a new member from Nepal ("Mount Everest country") came on but everyone had already left the chat room. Finally a member came on (who has changed her "Chat name" slightly), who had missed the chat. She had forgotten that it was Saturday! She has been lost on her days lately. She hopes that everyone is well. She has been making progress, at therapy, with the movement of her shoulder, but the pain is increasing rapidly. Otherwise, "I am doing well".