Summary of ECD Global Alliance Internet Chat 26 Oct 2013

8 Attendees

- A member is leaving, from Norway, to go to California, very soon. She is going to Copenhagen, and then takes a direct flight to San Francisco. And will be getting to San Diego by mid-week.
- A new member came on. She is from the UK (only a couple of hours drive from our other UK Chatter), but spends a lot of her time on a Greek Island. She is seeing the same doctor as the other UK Chatter, and has recently started methotrexate. Her dose has been doubled, and she wonders whether this could be making her feel unwell. The other UK Chatter is on twice as much again, but has no side-effects. Another UK patient has also seen the same Doc, and just started methotrexate too. Both had heard about this Doc from our Chatter!
- Members discussed whether they would be meeting, next week, in San Diego. One member from Europe is flying over, but the other European can barely cope with a couple of hours being driven about in a car, so he is staying put.
- A member introduced a "new to him!" internet acronym. ROTFLMAO. One of the other members knew it already. Rolling On The Floor Laughing My Ass Off.
- A member asked whether the San Diego conference is being videotaped. This is probably going to happen. [Editor's note: The first day of the Patient and Family Gathering on Nov. 1 will be videotaped. Plans are to make this tape available to everyone.] Also name tags were mentioned. [Editor's note: Everyone will have name tags in San Diego!]
- A member has recently had a phone call from Dr Haroche, in Paris, France. He said that he had treated 10 people with the BRAF inhibitor drug, with very good effects. This member is starting vemurafenib in December.

- Dr. Haroche also said that he had seen 104 ECD patients! Other members found this to be a surprisingly high number, when they had either never met another sufferer, or only met one (or two, tops)!
- A member came on, who has spent most of the last year caring for her husband. He has been having treatment for cancer (surgery and chemotherapy), and has just had an all-clear report. He only has one more operation to have. Dr. Janku is looking after her, and is keen to get her on the vemurafenib trial. He did not have enough tissue left from a biopsy, so more will be needed.
- A member asked whether others had problems with tremors. This member told us that the fronts of his upper thighs have been feeling either very tired, or weak. He has also had some trembling. He thinks that this may be due to the medication. His doctor isn’t keen for him to try vemurafenib, because he is stable at present so “ why fix what ain't broke”.
- One other member does get some trembling but doesn't get too bothered by it. It happens more often when she is tired.
- Our Spanish speaking member was present through the Chat, but we had no Spanish speakers, and none of us knew how to use the translator in Google in a “real time” mode. Using Google I have managed to translate some of what was said.
    - He has been having interferon, but it is no longer effective. He has had a biopsy taken for BRAF testing, but there is no result yet. He is concerned about the side-effects of vemurafenib. He asked whether the San Diego conference is being recorded, and whether it will be written about.