

Summary of ECD Global Alliance  
Internet Chat 19/10/13

8 Attendees

- A member, from the Southern hemisphere, started the Chat by telling us that he was sitting watching the dawn break. He was also feeling the effects of planting 200 plants at his church. He had been very busy – the day started at 7 am but a lot got done, and it will be interesting to see how the plants do, and what they look like as the months progress. He lives in Australia. The nearest bush fires to him are in the Sydney area, and are 1100 km / 700 miles way so he is safe, but he is feeling & praying for the people affected.

He will be at the ECD gathering (he wants to meet up with some of the people who have been so supportive to him, and his wife, during her illness). He leaves for San Diego on the 31st October, and will, later on, spend a few weeks visiting friends around the US and UK. Kathy has just let him know that she has lined up the local TV station, for an interview about ECD, on the day that he is visiting her in DeRidder.

- A member from Norway told us there is only one more week until she, and her boyfriend, leave for the US. It is getting cold in Norway, now, but they have had some nice autumn days. She is not looking forward to the long plane trip next Sunday, flying directly from Copenhagen, Denmark to San Francisco! And then, there is the 10 hour car trip from San Francisco to San Diego. Another member told us that that car trip is fantastic! Her son was stationed in Monterey for several years, and she told us that “there are some awesome sights along that road”. The drive will involve a lot of “seat time”. Members generally found sitting, for a long time, difficult. A few pit stops along the way will be necessary.
- Our Norwegian member is scheduled for a MRI and a PET scan, before starting treatment with the BRAF inhibitor drug in December. She is going to be staying at the hospital hotel, in Norway, for 5 days to do all the tests. She is expecting a call from Dr Haroche (she is also planning

to meet him in San Diego). "Finally, things are happening here" she said.

- A member has had his first bone scan since starting interferon. He watched the monitor, and could see that the disease was spreading. From the report, it has spread a bit in his legs. They want an MRI scan done to assess how much the disease has spread. He is having trouble because the Docs are not communicating, again. A bone biopsy is needed to get a definitive BRAF result.
- A member had been to his family Doc recently, and she changed his anti-depression medication. He is not sure that he likes this medication to be changed.
- Members discussed their interferon medication. One was taking the standard interferon preparation; 3 injections a week. One was on Pegasys, which is the "pegylated" version of interferon. This only needs one shot a week, because it isn't excreted ("thrown out") by the kidneys as quickly as interferon is. It's still interferon, but with a bit of chemical stuck on it to slow down the excretion. So you only need a weekly shot! Pegasys is quite a lot more expensive than the ordinary interferon.
- A member came on who had almost slept through Chat time! The sound of rain had helped her to sleep. Her area has had ten days of rain. Thankfully, yesterday was beautiful, and she had got out.
- A member said that he had "another trip to look forward to". His wife wants to go to SC, after San Diego. This is to see family. He thinks that will take some pressure off him. He said that it is "tough, for me as a guy, not to be able to do for myself". He hates to see how tired his wife gets, and it makes him feel "a burden".
- A member came on late, but there was still one Chatter left. The new chatter was the wife of a man in Belgium, who has ECD and has been on interferon for 1 month. This has made him very tired. He does not speak English.
- Both of the remaining Chatters were hopeful that the San Diego meeting will be helpful.