

Summary of ECD Global Alliance Internet Chat

11Jan2014

12 Attendees

- A member from Europe is experiencing delays in hearing any news from the medical team looking after her husband. She has rung many times, but the doctor is not available (holidays, Doctor Congresses) The good news is that they have found another ECD patient in their country. They have been in touch 3 times, and it means that the member can use her own language (Dutch) rather than struggle in English. The other ECD patient said that his doctors had diagnosed 2 other people with ECD, after him. They were people who had been treated as "rheumatic" for many years.
- A member is trying to use a program that recognizes speech, and then turns it into text. These programs have to "learn" your way of speaking, and take a while to get going. Lots of fun to be had along the way!
- Two of the UK patients discussed whether they might both go to the third UK patient's house for "tea and cakes". They all see the same Doc (in Leeds) and had hoped to meet last month, but this didn't work out. Hopefully it will this time.
- A member who has recently started vemurafenib is now "going well". The joint pain that she had has now reduced, and she said that "I feel like I am living again", and is able to exercise. She had a check up this week, did all the tests, and everything was OK. Her MRI showed a 3 mm shrinkage of a lesion in her spinal cord!!
- A member who was scheduled to start vemurafenib had this delayed because of bad chest involvement. He has had a course of antibiotics, and has noticed some improvement in his lungs. The start of vemurafenib has been delayed until he has had more scans. He has a heart MRI and a brain MRI this week. He hopes to start vemurafenib soon after. His Doc (Prof Pete Hillmen) is in contact with Doc Haroche about him. His Doc told him that if ECD is not caused by BRAF, it will most likely be caused by a failure in another part of the signaling pathway. vemurafenib switches off the cells that have been permanently on, and reproducing uncontrollably.
- Another member who has just started vemurafenib developed acute pancreatitis (a sudden onset inflammation of the pancreas gland. This is attached to the bowels just below the stomach, and produces enzymes for digestion. These are chemicals that break foodstuffs up. Acute pancreatitis is often a serious, life-threatening condition). He thinks that there have been two documented cases of vemurafenib being associated with pancreatitis. He expects to be off vemurafenib for about two weeks, before trying again at a lower dose to see what happens. He was on 4&4 so he expects to be on 2&2 (2 tablets in the morning and 2 tablets at night).
- A member who has been taking methotrexate thinks that this is now helping with her leg pain. She is still having problems with balance. The steroids that she has taken have given her the start of cataracts. As she is an artist, she hopes that they won't progress too quickly.
- We were told that the son of one of the Chatters has just had a biopsy done of a large nodule on his lung, and this has been reported as showing Hodgkin's lymphoma. He has been having treatment for ECD for a year already. They saw Dr Diamond this week, and he said that he had

spoken with Dr Haroche, and they have never seen ECD together with Hodgkin's. They advised treating the lymphoma first.

- Members mentioned how rare ECD is, and how they were pleased that the Docs seemed to be talking together about it. It was mentioned that one of the big upsides for the ECD Global Alliance that it gives the doctors more likelihood of working together and learning faster.
- A member has had her food stamps cut from \$149 to \$68 a month. Someone from the SSA will hold a session at the Patient and Family Gathering in Bethesda in September. This will be an excellent opportunity to talk to someone in the department.