Summary of ECD Global Alliance Internet Chat on 06 July 2013

13 Attendees

- Before the Chat started, a member left a message. She had gone to her cousin's wedding, so she couldn’t be on the Chat. She told us that her pain has been getting worse, and her doc is thinking about changing treatment from interferon to something else. She is otherwise well, and taking advantage of the good weather to ride her bike and walk her dogs.

- A member came on to say that she had met another member, the previous day, on her way home from vacation, in Philadelphia. She had thought that she would never meet another ECD patient. This member has not been on the Chat for quite a while. A member told us that he had met two other ECD patients (one of them twice)!

- A member had been to the NIH in March, and ECD lesions were found in her cerebellum. She had previously been on interferon, but this was not good for her kidneys. She was on kineret for 6 months, but this didn’t help with the lesion in the cerebellum, although, her elbows, and knees, felt much better. She is going to start a new treatment next week. She hopes to go to San Diego in November.

- A member came on who had not been on the Chat for the last few weeks. He has been really sick after chemotherapy with clofarabine. It has taken him weeks to get over it. He lives in Bay Area of San Francisco.

- Teeth were then discussed. Some members have lost teeth due to the ECD. They just break off at the gum line, or crumble away. A member has recently had a tooth fall off, but this was a crown, and it probably is not related to the ECD.

- A member, who was diagnosed in 2010, told us about his symptoms. He had fatigue, wobbliness, and Diabetes Insipidus.

- Our Brazilian member has recently been to Sao Paulo for a PET scan, and an MRI of the left foot. This member is on interferon, and is having to “fight” the side effects.

- A member is staying at “MS camp” (a rehabilitation centre for MS patients).This has involved a lot of exercise. She has been trying a drug Fampyra (4-aminopyridine), which is used to try to help MS patients with their walking. It is a potassium channel blocker, and seems to be having some effect.

- A member told us about a recent visit to Dr Janku at MDA. This went well, and he is going to get together with her doctor to plan where to go next with medication.

- Dr Janku is checking another member, for the BRAF factor, but he is doing so well on Gleevec, that he does not want to change medication.

- Many members told us about having ECD lesions in the cerebellum. This was often accompanied with slurring of speech, double vision, and unsteadiness.

- A member has, recently, been on 2CDA. She has had 6 cycles, each lasting for 5 days. The lesions in her cerebellum have gone. It was said a number of members have had treatment with 2CDA. This member was asked about side-effects. She was tired but thinks that may have been, partly, her own fault, as she keep kept working during treatment. She did have a low blood count, and an extremely sluggish digestive system. A member told us that there can be side effects 3 weeks after starting 2CDA, but her son had thought they were worth it. The 2CDA, more or less, stabilized him. He had a low white cell count, a lack of energy, and food had a metallic taste. Chocolate was the only thing that tasted half-decent (what a shame!!).

- A member, whose wife died due to the effects of ECD, was asked about her symptoms and treatments. Her first symptoms of ECD, that we KNOW were due to ECD, were bilateral retro orbital lesions, surrounding the optic nerve (a common location for ECD). She was 45 when these were found, but she was 50 before it was diagnosed as ECD. Treatments that were tried were: radiotherapy, prednisone, and Imuran (azathioprine) the first two slowed, but didn't stop the lesions growing. The Imuran worked. He wonders whether some other things, over the previous decade, were ECD linked, but he will never know.

  Her final ECD lesions started in the middle of the Pons, and extended into the Cerebellum. Her doctors, at Austin Hospital Haematology Department in Melbourne, Australia, felt that Methotrexate (high dose) had good effects.

- Members discussed their plans for going to San Diego later this year. See http://events.constantcontact.com/register/event?llr=vxnuk4lab&oeidk=a07e73ss7vic308c2f1 for more information.