

Summary of ECD Global Alliance Internet Chat

02 Jan 16

10 Attendees

- A member who has been having a lot of pain from her shoulder has had a steroid shot in the joint 4 weeks previously and "aggressive" physiotherapy. She has a 65 pound dog and wants to be able to walk the dog, and to stay on her feet! Her family had rented a "cabin" with 6 bedrooms, in the mountains of North Carolina, for all of their married kids and 3 grandchildren. Their youngest son is in New Zealand, and they hope to fly there in March to see him.
- A member asked whether anyone with brain lesions, particularly cerebellar lesions, had ever had PET scans. The answer was yes. She, herself, has never had a brain PET, just PET on the rest of the body and MRI of the brain. For two members, all PET scans have all been of the whole body.
- The brain PET scan is very sensitive, and you are not allowed to be texting, using your phones, using MP3 players, watching TV, or reading while you're awaiting your scan for 1 hour. This is to allow the radioactive tracer (which you have just had injected into a vein) to be taken up by active tissue and left alone by the rest of the brain and body.
- One member had had cerebellar lesions at first, but is now stable and in remission. The "scars" that they left still affect him. He falls about and slurs his speech like he is drunk. "10 years of being drunk is not much fun." The discussion then turned to American Civil War History. The member who has been "drunk for 10 years" asked "How long did Cooter Brown keep it up?" Cooter Brown was around during the American Civil War, and he stayed drunk ALL the time so that he wouldn't be called up to fight. According to Google, Cooter Brown lived along the Mason-Dixon Line at the time of the Civil War. He had family on both sides, and, not wishing to be drafted by either the North or the South, he decided to get drunk – and stay drunk all the time– so that he wouldn't have to fight in the war. Inebriety has been measured against Cooter Brown's extended binge ever since.
- The member who originally raised the topic of cerebellar lesions had a brain MRI in December which showed that the pituitary stalk was not as thick as it had been, but that the lesions in the cerebellum were still there. She wants to have a PET scan to see if these are just scar tissue, or if there is activity in the lesions. She is on a dose of 2 in the morning and 2 in the evening now. She thinks that Dr. Diamond might change this to D (Dabrafenib). This drug is supposed to be the functional equivalent of vemurafenib (V), but with fewer side effects.
- Someone wondered whether scars were irreversible, but that lesions are reversible with treatments? The general understanding was that scars might not be reversible. She was asked whether she knew the reason that she might be changed from V to D. She thinks that Dr. Diamond wonders whether her shoulder problem was due to V.

- A member had browsed the Erdheim-Chester Global Alliance Facebook page, and found someone from the UK using D. He was asking if anyone had any experience of this. D is probably not being used much at all yet. There are no clinical trials using D alone, and the chance of getting V authorized by insurance companies is definitely much higher than for D.
- We were told that 2 ECDGA members (one from Ireland, one from Washington State) were on the D and T study at NIH, and they were both at the conference in Houston.
If you want to see the criteria for getting onto the trials follow this link- <https://www.clinicaltrials.gov/ct2/show/NCT02281760?term=NCT02281760&rank=1>
There is a size threshold for lesions. At least one must be 1 centimeter or larger. Also you must have had ECD proven and to be BRAF+.
- A member who has been having V for some years now said that her lung capacity increased from 90 to 96%.
- A member who had been due to go to NYC for investigations is having them done locally in Orlando (MRI and PET). The PET will be a whole body scan and the MRI is of the brain and orbits. She is BRAF- and takes sorafenib instead of V. She said that "I always feel awful on this drug". It has lots of side effects, like V, and her doctor has her taking it according to how "the side effects are doing". She is anxious to get her scans done to see if the drug has done anything. Her OCTs (a test that looks for edema of the retina) have been better.
The side-effects have been lots of skin issues, gastrointestinal, bruising, etc. Her head always feels "off", and though the macular edema has been better, her vision is unpredictable.