

## **Summary of ECD Global Alliance Internet Chat** **22 Aug 2015**

10 Attendees

- A member told us that she had a brain MRI on August 3<sup>rd</sup>. There were still lesions in the cerebellum and pons, so "still no driving". She also had a MRI on her shoulder. It showed that the biceps tendon was very inflamed where it inserts at the shoulder, plus it was encapsulated, so she is now on 5 days of steroids.
- Another member had had a head CT with contrast a couple of weeks ago. The Professor who organizes his care rang him at home, and said "No ECD" but the brain had shrunk a bit. "Age" he said!!
- A member in the US said that she, and her husband (who happens to be a psychiatrist), watched, and enjoyed, a TV series called "Doc Martin". It is a British made comedy about a family physician. The UK member (who was a family physician himself before he got ill) said that he had never, ever watched it!
- A member told us that she was on a trial in St. Louis and takes a dose of 3 in the morning and 3 in the evening of vemurafenib (V). Her primary doctor is at Mayo Clinic in Rochester, MN. She is having problems choking on food. She did a swallow test, and had an endoscopy (camera down to your stomach), but nothing was seen. A few other members said that they were on an acid reflux medicine.
- A member told us that her right arm has "really begun to shake". She thinks that this probably due to the ECD in the brain, but wonders whether it might be due to V. She is taking 2+3. A member on 4+4 doesn't have any problem with shaking. One member told us that he sometimes gets a "weird feeling down his arms that lasts about 5 seconds". Two other members have had shaking of their arms. They had both thought that it was due to the ECD.
- Members registered for Houston all said how much they were looking forward to meeting each other in person.
- The difficulties that some members are having with insurance companies were discussed. A member on one of the trials has all of his scans covered, but he will have to switch his insurance as soon as he gets off the trial. He has GHI, and he doesn't "like that insurance". You are only covered for Vemurafenib treatment if you have melanoma. His wife's insurance covers the drug, no questions asked.
  - A member, whose son has ECD, told us that he has a pet scan every 2 months. He has dual coverage with BC/BS, and they have never refused to pay for the scans.
  - A member had a PET scan at the NIH. Her insurer, BC/BS, is now denying one (even though they have never even paid for one). She needs it because she has "some sort of something" in her right lung. This was picked up in April at the NIH, and she needs "another look" for her private doctors that she sees Lexington. She thinks that if she can't get the PET approved, an MRI of the lung should show what's up.

A member on a trial has a PET scan every two months. Her insurer says that she can't have any more, so she will start having CT scans every 2 months instead. Her husband has been going "round and round with the insurance company" about this test.

Medicare only allows for 3 PET scans a year. For the member who has Lymphoma and ECD, this limit makes it difficult to keep tabs on the diseases.

- Difficulties in getting Kineret were talked about. One member, who has had trouble with Medicare over this, gets hers from "Kineret on Track". This is a Patient Support program run by the drug company. MD Anderson helps with this, and it has no connection with a person's insurance company.
- In view of the recent New England Journal of Medicine paper about vemurafenib, the insurance companies should start to change their attitude to requests for funding.
- The amounts of radiation that we all get exposed to were discussed. CTs and PET/CTs use radiation to obtain their pictures (MRIs do not!!), and we sure do get through a LOT of them. We were told that MD Anderson is doing a study on the effects of radiation.
- A member came and told us that the last week had been "uneventful which is good"! He had had no doctor visits, and that is quite enough between his ECD visits and his visits to his transplant doctor. He had a kidney transplant (his brother was the donor) in February of 2014. Doctors thought that he had retro-peritoneal fibrosis, but later discovered that he had ECD and was BRAF positive.
- Others bemoaned the number of doctor's visits that they have to go to. One has weekly labs and OCTs (an eye-test). Another has monthly labs. One, on the St. Louis trial, has monthly labs. They are done again when she visits her primary doctor at Mayo clinic.
- Blood pressure was next talked about. Many members were familiar with the "white coat syndrome" (your blood pressure goes up if there is a doctor about, or if you have the test in a clinic or hospital).
- Vitamin D and calcium supplements were mentioned. Quite a few members are on vitamin D supplements, and some take calcium supplements, too. Two members told us that they were on Bonviva, a bisphosphonate drug. This drug family is used in the treatment of osteoporosis (thinning of the bones).
- One member told us that a friend's mother was always told by her doctor to take zinc whenever she "felt something coming on". The doctor told her that this would "help her immune system". [Summarizer's note; I never came across this advice in 20 years of being a practicing doctor myself!]
- We were all reminded of the dangers of sun-exposure when you are taking V. It was also said that the wind is worse than the sun. One member needs to stay in on cloudy days, if it is windy.