

## **Summary of ECD Global Alliance Internet Chat** **16 May 2015**

7 Attendees

- A new member started things off by telling us that the request for coverage for Kineret, as treatment for her husband's BRAF negative ECD, has been denied by their Medicare insurance. The next step is a hearing with an Administrative Law Judge, and she wondered whether anyone else has had a similar experience.  
A member said that he had the same experience in July 2008. It was a very informal court sitting. There was a judge there, himself and his lawyer, and a representative from Social Security. The judge asked questions of the Social Security rep, and then of his lawyer. The judge asked the Social Security rep; with the restriction and limitations the aged ECD patient has, how many jobs would be available to him? The social security rep answered "zero". Then the judge asked the member some questions; how long could he stand, how far could he walk, how far could he drive, and how long could he work on the computer? The judge wanted to see if he could work on the computer from home, or drive a cab. The member said that he couldn't. His lawyer then spoke again; reminding the court of the limitations ECD patients have, as well as the devastating side effects of the medication. The judge took all this information and said he would be ruling in a few days. The ruling was in the member's favor.
- A member told us that she was having "some issues with my medication refill", but otherwise has been "pretty good". But she has been tiring herself out "trying to get things done, and helping others".
- Another member said that he knew how she felt. "You want to do more than sleep, every one of us wants to be able to do something to show we are still useful." This member has the hobby of woodturning. He is in the finishing stages of making an Applewood lamp, and a Cherry and Applewood miniature birdhouse. Spring, summer and fall he works on some vegetables, flowerpots, and his woodturning. In the winter, he has guitar lessons.
- A member came on who had not been on the most recent Chats. She has had 2 weddings to go to, and she was at the NIH, in the last week of April. She was due to go on to the phase 2 drug trial, but the lesion in her brain stem was 2 mm too small for her to be eligible for the phase 2 study, as the lesions need to be 10mm in size. She has just started on Vemurafenib (4+4) with a private oncologist, Dr. Rachel Harper, at the Lexington Clinic in Kentucky. Dr. Harper has never treated anyone with ECD before, but she is more than willing to treat the member. She has spoken to Dr. Estrada-Veras at NIH, and put her on vemurafenib (V), because she knew that fighting with the insurance company over the Dabrafenib and Trametinib drugs would be a waste of time. Insurance is covering the V. She has just taken 2 doses so far, and has had no side effects yet, apart from dizziness. She doesn't have any issues with her vision, but her oncologist told her not to drive because of the dizziness. Another member also has dizziness, but was never told not to drive. She just ensures that if "I get bad, I can pull over".

- A member with eye problems said that she had to increase her dose of prednisone because her macular edema was worse. She doesn't know when she will be back at Memorial Sloan Kettering (MSK) again. She is BRAF negative, and had been taking a drug called Sorafenib. This was stopped, but has now been restarted.
- A member is moving to San Diego. He has been on one of the trials at MSK. He is seeing Dr. Diamond at the end of May. He is scheduled to see a Doc in San Diego at the beginning of June. He is still taking V on the trial at MSK, but is pulling out of the trial, partly because of the move to San Diego, but also his goal is to find a maintenance regime. He is in remission, with "no activity" on his PET scan. He is taking 3 pills in the morning and 3 in the evening of V, but he is sure that he will be OK on a much lower dose, say 1+1. "But you cannot remain on the trial if you are on such a low dose". He said that at 4+4, you need to watch out for side effects, such as hand-and-foot syndrome, rashes, liver/kidney damages, etc.
- [A retired doctor writes; it can take a few days before you see any significant side effects, as V has a long half-life, and takes a while to reach a "steady-state" in your body. This is also why it takes a few days for side effects to go away, after you stop taking it, because the drug only leaves your body slowly].
- The member who has just started V is already having some tingling. She was advised that if she is getting tingling on the hands and feet, she should make sure that she wears loose clothing, not wear socks or shoes, and keep her hands and feet cool. Also to stay away from water that is too hot/warm, when on a high V dose.
- The member giving this advice began the V trial nearly one year ago. He started on 4+4. He got down to 3+3 after 1-2 weeks. He had suffered some serious side effects, but based on the improvements on his eyes (from nearly losing his vision to being 20/20), he has "never complained about them".
- If you are on the V trial and can't tolerate even 2+2 daily, then they would allow you to take it every other week. Because it takes about a week for the side effects to start, you get to recoup and stay on the trial. More often than not, participants of the trial are progressing well on this regime.
- A trial for BRAF negative patients was mentioned. [Kathy's Note: We are hopeful that US trials will be open soon for BRAF-negative patients. We'll be certain to announce the opening of these trials when they are approved.]
- A member said that she had been started on Bonviva (a biphosphonate drug used in the treatment of osteoporosis). She asked whether anyone else is on it (summarizer's comment: "I am!"). She was started on it before she had V, because her urine test at NIH showed increased telopeptides. This is a marker for increased bone turnover.
- A member came on at the end. She was sorry to have missed the Chat. She had been out walking. This must mean that she is getting better!