

## **Summary of ECD Global Alliance Internet Chat** **28 Nov 2015**

9 Attendees

- A newly diagnosed ECD patient had come on and left a brief message in the days before the Chat. A message was left for him telling him when the Chat would take place.
- The member who managed to be on the Chat last week, partly because he had taken medication that day that had stopped him from drinking any vino, left a message to say that this hadn't been the case this week, so he wouldn't be on the Chat.
- Another member has just had his ECD diagnosis confirmed. He is BRAF+ and lives in Canada. He is able to access vemurafenib (V), but the difficulties will be the price tag and the questions about insurance coverage.

He was told that there are more studies starting up in New York. The cost of insurance for traveling to the US would be large. He has also had his neck fused, and the idea of many trips worries him.

There is a hospital in Toronto, Mount Sinai, which may be a new place for him to go to. He has a DVA brain lesion (Developmental Venous Anomaly), his legs "lit up" on scan, he has hairy kidneys, and maybe the heart is affected too. He is 49 years old.

Before starting V, the treating team will do baseline scans and blood work. They will be getting V in Canada pending authorization. V is available there. The problem is the price tag of the medicine. Outside the hospital setting it is very expensive - \$12,000 a month. They are waiting for insurance approval, although this shouldn't be for too long. It would take much longer if they have to try to find a secondary resource, and would be even worse if they have to find the money upfront. So far, the insurance company seems positive.
- For another member on V her Blue Cross Blue Shield (BC/BS) insurance covers the cost. And yet another member on V is switching to his wife's coverage in January, because her insurance does cover the V.
- A member who has done very well on V might be coming off the trial soon. His doctor is lowering his dose to 3 in the am and 3 in the pm, because the disease is minimal now, and there is no need to be on full dose. Then the dose will go down to 2+2. The doctor didn't mention anything about coming off V, but the member will probably come off the trial once he gets on his wife's insurance. He will be in the LOVE trial, where they will restart V if there is a relapse. Unfortunately, he has started to get pain in his left rotator cuff.
- Side effects of V were discussed. It was said that these depend on the individual. One member said that he didn't get any side effects "that hurt" until a few weeks ago. He has been on the full dose of V for 6 months. He then started getting headaches. They weren't unbearable but he knew that they were there. He also had some hair loss on his legs and arms. His doctor said that he was abnormal (probably in regard of his lack of side effects, not abnormal all over!).

He thinks that because he was on such a high dose for a long time, good results came quickly. He was able to jog within a couple of weeks of starting treatment. He has noticed that he is now severely sensitive to sun. He is scared of the long term effects from taking V.

- Another member who has been on V, and is now in remission, is now taking 2 pills a day, and wants to go to one or none. He thinks that V has "taken care" of his ECD pretty well, but V is not his "friend". He is concerned that new side effects may come around with time, like damage to the liver or other organs. He doesn't think that V is something that you can take for a life time, even if you can afford a low dose.
- A member, who is changing doctors, sees Dr. Diamond in the next week. She is also seeing an orthopedic. She is looking forward to getting an answer to her terrible shoulder/arm pain. A PET scan in August didn't pick up anything "malignant". She had a cortisone shot under x-ray, a couple of months ago, but it didn't help at all. She doesn't take any pain killing medicine because nothing bought "over the counter" helps, and she doesn't like narcotics. Tylenol hasn't helped. She does use some homeopathic cream that her cousin sent her. This is just a bit "soothing". She also works her arm in a warm water pool about 4 times/week. She can hardly raise a mug of tea without pain. She is, also, developing tremors in her right hand (this makes reading the paper hard!). She gets to drive her car in the next week with an occupational therapist (OT), so that she can get permission to drive again after 7 months!
- Members on trials of V mentioned the regime of tests that are performed. For one, he has a PET body scan, PET brain, MRI brain, blood work, and sometimes a CT chest and EKG. Sometimes he sees a dermatologist.
- Another has blood work and EKG every 4 weeks. Her CRP (a marker of inflammation) went down at first with the V, but it is going back up now.
- Lastly, a member who has now come off a trial, said that he used to have MRI brain, with and without contrast, CT, PET, sometimes a PET of the brain, every other month. This all took a lot of time and he couldn't eat all day! Now, he just has one PET every 4-5 months.
- After we had finished a message was left asking whether anyone knew "if SSDI will pay for all ECD prescriptions?"