

## **Summary of ECD Global Alliance Internet Chat** **10 Jun 2017**

7 Attendees

- A member said that he was now down to see the doctor just once every three months. He is on the vemurafenib (V) trial and sees Dr. Janku in Houston. Most of his other doctor visits are in his home town. Appointment intervals were discussed, and they varied from 3 to 6 months.
- It was said that Dr. Janku is relocating, but nobody had any details of this.
- At Memorial Sloan Kettering, they are reimbursing some participant's travel expenses. Although the member who goes there is not sure who qualifies. The drug company is helping to provide the assistance. A member said that he thought a few of the very earliest participants, on the V trial, wanted to drop out and go off-label. However, since they are providing the most comprehensive data, the drug company wanted them to stay.
- A member who goes to Houston doesn't get travel expenses. This member usually flies to Bush airport. The shuttle takes about 30 to 40 minutes to get into town.
- The member who has recently had shoulder surgery said that if her brain MRI looks worse, then she may have to go on another MEK inhibitor drug trial under Dr. Diamond. Vanderbilt has some trials and she is only three hours from there, (and her son and daughter-in-law live in Nashville). But she has already been on two kinase inhibitors, and thinks that this will make her ineligible for the trial. When she met Dr. Janku in Houston at the ECD conference, he recruited her. But, having grown up in Houston, she didn't want to go back! Another member said that after living there for 35 years he "truly" understood her feelings. A member said that he had lived in Houston for two years of grad school. He had not liked the city at all, and "just wanted to get out."

She is going to see a rheumatologist in July to try to find out if the shoulder joint stuff is from an autoimmune disease (in addition to her ECD). Her Lyme Disease test came back negative.

- A member in Norway stays at a patient hospital when going for checks. She has just been for a two week rehabilitation stay at the hospital, with a warm water pool and physical therapy. She was told to rest so much that there was not much time for exercise!
- MD Anderson does not have a place of its own for patients to stay, but the local hotels have special rates for MD Anderson patients.
- A new member came on who spoke Spanish. [I will quote her actual messages, one of the Chatters was able to translate a bit.]

"Saludos y cariños espero que estén bien empecé un plan médico con direccionando por el Dr Diamond y espero en nombre de dios salir adelante no ha sido fácil pero no podemos perder la fe en Dios y la Ciencias médicas"

Translation(ish) "Greetings and love hope you are well started a health plan of Dr Diamond and I hope in God's name go forward has not been easy, but we must not lose faith in God and the medical sciences."

"En estos momentos estoy con Anakinra, pero el plan de medicamentos es trametinib o cobimetinib"

Translation She said that she is on Anakinra now, but may go on to Dabrafenib (D) or Cobi.

"Problema que estoy presentando es que no tengo equilibrio y mucha debilidad, regidez en pies. Agradezco la luz que me brinda a través de este chat"

Translation "Problem that I am presenting is that I have no balance and a lot of weakness, stubbornness in feet. I appreciate the light that gives me through this chat."

- The wife of the member living in sheltered accommodation said that he is still on half the dosage of the V. He had two doctor appointments this week, neurologist and psychiatrist. His QT interval had lengthened while he was on the normal V dose, so it was reduced. He will be going back this week to see if it has shortened. She suspects that some of the other drugs will have to be changed. She thinks that he is having low grade fever again. Earlier that week he seemed hot and had a resting heart rate of 100bpm. Later in the week he seemed a lot better. They are still having to cope with some other problems too, particularly with how his depression is affecting his behavior.
- Dizziness was discussed. One member has been having some dizziness, but he is unsure whether it is because he doesn't sleep enough. His legs seem to be fine. Before he was diagnosed, he would get dizzy looking at the computer. This later transformed into very serious headaches.
- Another member who is troubled by dizziness said that it is not vertigo. She has been checked out for that many times. She gets dizzy every time she turns her head upwards or sideways. And she stumbles. It seems to start in her brain (not the inner ear). Her brain MRI this month "may not be stellar." She also said that she has had a return of her low grade fevers in the evening and sweats.
- Although she is not keen on restarting therapy it was said that she may need to explore going on low dose of D or V. A member who has had V treatment said that he has been fine when taking one or two V a day. He now takes one V at bed time daily. Another member said that he was "fine on 2+2."
- The member whose dizziness turned into severe headache said that then, he had so many active lesions in his head that he was going to go blind. But all the doctors were not worrying about that. They were all worrying about a tumor in the back of his neck that was blocking blood flow to his brain, which could kill him first before he lost his vision. He had, and probably still has, masses in his orbits, but his optic nerves are normal now.
- After the Chat had finished a member came on and said that he had been at the Belmont Stakes. It had been a beautiful day. Dr. Diamond has reduced his dose of dabrafenib (D) to 2+2.