

Summary of ECD Global Alliance Internet Chat

17 Jan 2015

6 Attendees

- A member had been to his local center for PET-CT scan. This was an hour drive away. On arrival he was told it was all off, as the isotope injection wasn't up to scratch. The positrons hadn't eaten up all their breakfast, and wouldn't come out to play!!
- A member told us that she had recently been taken off Anakinra and her chills and fevers are back. Other members had previously had some night sweats, but not in a long time. One said that she had had a terrible time with sweats while she was on chemo for her lymphoma. Dr. Diamond had stopped the Anakinra, and she will be going on a different drug. The doctors do not know whether the Anakinra has been effective anywhere else, but it certainly helped with the fever and night sweats. She had not seen any improvement in her eye symptoms. The Anakinra had very few side effects, excepting the usual injection site irritation, and "It made me feel so much better". As soon as she stopped taking the Anakinra, the fevers and chills started back. A member said that she should, perhaps, suggest stepping up the dose, to see if it would work on her eyes, instead of dropping it.
She will be flying to NY on the 27th to discuss this, and have MRI and PET. She has an appointment with Dr. Diamond on the 29th, at 3:30pm.
- Another member will be in New York for an appointment at 3pm, so they will probably meet at the doctor's office! This member has been on vemurafenib (V), and is now "in remission" (ie. no activity on PET-CT). He had "a bunch" of scans earlier in the month, so he will not be having any scans this time. It's unusual to go to Sloan Kettering twice in a month, but they are moving back to the "regular" schedule.
He said that he may have a business meeting on 28th, which would make his trip even more productive. He has been able to do this a few times. He is still managing to work "as if nothing has happened"!
- A member who has been on V for the last year has had no more progression, and is "in remission". Her next check-up is in one month. She said that the V has given her "lots of strength and energy". She feels twice as strong as she felt one year ago, and takes only 3 doses a day.
- The member who has recently had to have chemo for a lymphoma is doing fine. She has just completed 6 R-chop chemotherapies. "My body is old, and I am trying to get back my strength".
She has been restarted on Anakinra because it was working well before the chemo, and her PET-CT was so much better. She is BRAF positive, and it was suggested that she should maybe try V, or one of the other drugs that are on trial at NIH, or even propose the use of the combination V & Anakinra in an experimental plan and report the results -a possible future clinical trial.

- Members discussed the effects of V on their strength. The member who feels stronger is only taking 3 a day. It was said that if you are on 2 in the morning and 2 in the evening or lower, you may feel stronger, but it's different if you are taking 3+3 or 4+4. One Chatter was taking 3+3 a day, but he thinks that his eyes are reacting to high dose more effectively. He had started with 4+4, and the drug "knocked me out" within a week. He could not walk or use his hands, but his eyes improved (he had almost lost his sight) during the same time.
- A member arrived late, because she had been at lunch with an old friend from grade-school. Her shoulder is doing better. Although she still has a lot of pain, motion is perfect now. She has therapy twice a week now. She is doing well and has been stable on Anakinra. She also doesn't get sweats. She will see her doctor in February and if all is good, she will be coming off medication. She sees Dr. McNeer from University of Chicago.