

Summary of ECD Global Alliance Internet Chat

23 May 2015

9 Attendees

- A message was left by one member saying that he had only just got home from a 4 and ½ hour Ataxia Self-Help Group meeting. He was “all diseased out” and wouldn’t be at the Chat today.
- A message was left for the chatter who had logged on during the week. He was told about some of the trials that are presently being run.
- A member who has managed to reduce her vemurafenib (V) to 1 in the morning and 1 in the evening said that she was feeling good. She does get a bit stiff if she sits around too much. When she was on 2+2 V, she had a lot of pain in her wrists and fingers. She had to reduce her dose to 1+2, and is now only on 1+1. She had only been able to tolerate 2+2 for 3 weeks. It seems that the dose that different people can tolerate varies a lot.
- A member who had recently started on 4+4 had developed a rash after just 5 doses. Her oncologist told her to stop it for 2 days, and then she started back on just 2+2. She has had no more rashes, but her right knee and right forefinger became very painful. Those pains are gone now, but her left wrist is now “so painful”. She asked the member who has been on V for a while, whether he had had 'tingling' all over when he started on the V. He said that he had had it, and that she needed to stay away from hot/warm water, particularly on her hands and feet, and that “sun is the biggest enemy when you are on V”.
- It was said that having a rash when on V is a sign that it is working. A member said that “rashes are good, as long as they don't get to the point that you're scratching too much and leading to infections”. This member’s dermatologist prescribed 0.1% triamcinolone acetonide, which is a topical steroid used to control the rashes. It has been working quite well for him. The other member who had a rash took an antihistamine, but found that this made her feel doxy so she stopped it. She has not noticed any clinical benefits from the V yet, but has only been on it for 1 week. She was advised that “you have to be patient with the V”.

One member said that he had been lucky enough to see very significant clinical benefits on his eyes, as soon as he started the V. It may take longer to see other benefits, if tumors/lesions are taking time to shrink. Members who had tumors/lesions in their heads compared notes. They both had odd feelings in their heads. The member who started V found that these feelings all went away when he started treatment. The only thing that is still bothering him (beside the sun and rashes -- both side-effects of the V) is eye irritation. However, he doesn’t know if this is due to ECD, or to side effects from the V, from dry eyes, or allergy, because any of these can cause irritation!
- A member with much reduced vision due to the ECD, has been having further problems. She has been told that she is in remission and that the ECD isn't coming back, but her vision has got a bit worse. She has adjusted to the new situation pretty well, but things like this are “always scary”.

- A member told us that she had been using Kineret, but was then diagnosed with a lymphoma, too! She had to stop the Kineret while she had R-CHOP chemotherapy. She has had 2 PETs since the last chemo, and they were clear. So, Dr. Janku has restarted the Kineret. She was tested positive for the BRAF mutation.
- One member was doing the chat from a hospital E.R.! His wife was having a lot of pain due to a urine infection, and was later admitted.
- A member said that she was doing OK. She is BRAF negative and has been taking sorafenib. This had to be stopped recently, but is due to be restarted. She has had problems with macular edema. This has improved a bit with increased doses of steroids.
- It was said that Kineret is great for symptoms. For one member, it got rid of her fever and night sweats, and she had felt much better while on it. She did not show improvement on Kineret, but she was only on it for 4 months.
- We were asked whether any of us had ever tried taking Turmeric supplements for inflammation.
- A member is coming off the V trial at Sloan, after one last visit. He is moving to San Diego, which happens to be where Dr. Kurzrock is now working.
He would like to seek her help in finding a long-term maintenance "solution". He wonders whether Kineret is a candidate for maintenance after V trial. He will definitely ask Dr. Kurzrock about it.
- One new development on the V trial is that some patients are allowed to enter the "LOVE" phase. This is where the patients can get off the drug, but are still "on the trial" for monitoring. If there is a relapse, then treatment is resumed.
- CRP was then discussed. CRP is C-reactive protein, and it is blood work that is a measure of inflammation. It could be a "Simple" CRP, or a "High Sensitivity" CRP. Members said that they would try to make sure that it is checked every time that they have blood work done.