

Summary of ECD Global Alliance Chat

27 Dec 2014

6 Attendees

- A member started things off by apologizing for having missed some recent Chats. He has been on Zelboraf [vemurafenib (V)] for just over 11 months, and is "quite amazingly improved". He can breathe fully now, and has no side effects apart from "zero sun tolerance", folliculitis (inflammation or infection of the hair roots in the skin), and he feels tired a lot of the time. He told us that these side effects are easily put up with. His lungs and heart would have packed in by last June. "This is just fabulous" he said. His next check-up will be at the end of January. He goes every month. His doctor has said that if these tests are ok, then they will drop the dose to two tabs a day. He is worried about what will happen when the V is reduced/stopped, but he supposes that the doctors will have more data by then to help to make their decisions.
- Another member on V has her next regular checkup in February. Her doctor wanted to cut down to twice a year, but she said no to that.
- And another member who came on is just starting out on his "V adventures". He has just had an MRI, but has not yet got the results.
- A member who lives on an island in Greece managed to stay awake until the Chat (time differences make it 10pm over there!). She is enjoying the sun in Greece, but struggling with walking, due to bad pain. This seems to have gone up into her hips now. She would like to try Kineret, as so many American sufferers seem to get relief from it.
- The member from the North of the UK, who has been doing so well on the V, told us that he had met up with some other members. Three attend the same doctor in Leeds. They have met at a member's house, and also in Leeds on a day when the member from Greece had flown all the way back for her checkup!! They had an enjoyable lunch together, and hope that it is the first of many meets. One of the rarer patient group meetings on the planet!
- Members mentioned their local weather, and the amount of snow they were having to deal with. Luckily, not too much yet!
- After these Chatters had gone, another member came on. He had missed this week's chat but sent us all his best wishes.