

## **Summary of ECD Global Alliance Internet Chat**

### **24 Sep 2016**

6 Attendees

- A short Chat with only a few Chatters. Those who had been in Paris had probably Chatted quite enough in their days together! A member came on to say hello in advance and to say that he would be in bed by Chat time!
- A member came on who has missed quite a number of Chats recently. He is on vemurafenib(V) and said that he was "doing pretty well". He is a keen woodturner and had been out in his shop that morning, starting to make Christmas ornaments. His hands are swollen and stiff, and he cannot make a fist. He can see lesions and feel hard spots under the skin. He can grip things that are about an inch to three inches, but has problems with things that are smaller or larger than that. It was said, by another member who has had V, that the hand problems are probably a side-effect of the V.
- Another member said that he was also doing well and had just got home from food shopping. He thinks that his wife has appointed this duty to him on Saturdays. "Sure beats cleaning the house, though." They have a routine on Sundays when they make their lunches for the week. Grilling chicken, making salads, and bagging grapes. "If you were here you'd think it was a sweatshop."
- Another member said that her husband shops on Sunday evening, and has done so for years. She is wanting to do her own shopping these days, just for the challenge!  
She is generally better than before. She is getting balance physiotherapy, and does a cardio workout at the YMCA each day on a bike, arc trainer or elliptical. Dr. Diamond told her in August that her body had been remodelled with the chemo. She thinks that he meant that some of her joint, skin and balance issues may not get better. She is trying to improve what she can, (i.e., the dizziness and her balance problems). But, if the lesions or shells of lesions in her brain caused her dizziness, then she may never get back to "normal".
- One member said that the only exercise that he likes is bike riding. Another said that he is still running on the treadmill daily.
- In Paris, we had been told that patients on V should stay on 1 a day until something new comes up, since ECD seems to come back in many cases after medication stops.
- Members spoke about their routines for follow up. One goes to see Dr. Diamond every 8 months or so. The doctor had first suggested follow up every 6 months, and he had said "how about 8" and the doctor said "fine"! He doesn't like to have too many scans, especially as his wife makes him sleep in the other room for 2 nights after the scan.
- Another member who has been doing well after V said that 8 months frequency should work for him. He is switching his insurance, and the new one has better coverage and includes Memorial Sloan Kettering, so he may go back after all. He also doesn't like scans at all. He thinks that if he is feeling great, then he doesn't care "about the scans too much".
- One isn't going to see her doctor till November. This will be 14 months since her last visit.

- And one has been down to 1 and 1 since August 20th. Her PET showed stability, but Dr. D didn't use the word "remission". She is having more joint issues and her middle finger, on the left is "triggering". She is going every 4 months, but hopes to be able to cut back to every 6 months next year.
- The getting of repeat supplies of medication was talked about. One said that her local oncologist prescribes the treatment that comes from Flint, Michigan. Dr. D tells her what to do, then she tells the local doctor. The local doctor and Dr. D talk as well.
- One said that he gets 3 refills at a time. He thinks that this will be his last month on full dose. He thinks that the doctor said that he can drop down once he has had a full 6 months on a full dose. After 3 months he can just call in for a new supply for the next 3, through CVS Caremark.
- A member said that his bloodwork had shown that his cholesterol had gone up to 210. But a recent test had shown that it was now down to 173. He said that he thought the rise had been due to all the barbecue food that he was eating!
- A member said that when he looks back, he realizes that he was missing/ignoring some signs that were not good. He thought that he felt great, but his eyes were bulging up slowly. He had some double vision and serious eye irritations. This did not count as being "normal"!
- Another member said that before he was diagnosed he was feeling great, meanwhile things were "brewing everywhere". He had gone for a knee MRI in 2009, and it came back saying that he had abnormal bone marrow. He had had further testing for lymphoma and leukemia, and that had come back negative, so his general doctor had told him that he was OK!