

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

### **1 April 2017**

8 Attendees

- A new member left a message. He/She said they were diagnosed with ECD in 2015. They had had to "beg" to have tests done. Then they wanted to give medicine intravenously, and asked someone near where he lives to do it. He feels that "it" is just in his lungs, (he has worked in a hazardous dust environment for over 20 yrs).
- A member who has had treatment with vemurafenib (V) and dafarenib (D) came on before the Chat to tell us that he wouldn't be on the Chat that day. "I have a million things to do today. I will check back later to see what I have missed. Hope all is well."
- When the Chat started, a member came on and told us that her walking was "terrible" and she did not know why. It has been bad for 3 weeks now. She wondered whether she had done too much exercising, as she had felt completely exhausted afterwards, and her legs seem stiffer. She has had no pain and is due a check up in 2 months. She has an appointment with her primary doctor this week. She is planning on asking for some sick leave from work. It was suggested that she might scale down on her exercise, but she said that she "feels terrible when I don't exercise". She walks outdoors with her walking sticks, but hasn't been out lately. She has also had a couple of falls.
- A member being treated in Houston flies there every 3 months. His scans are pretty stable with a slow, small improvement. A nurse at MD Anderson once told him "look honey, around here, nobody dies from stable."
- Some travel support is being provided for patients who were enrolled early in the Vemurafenib Trial at Memorial Sloan Kettering (MSK) and continue to return every 3 months. This is provided mainly to those who have to pay a lot on travel and lodging to stay on the trial. A member thinks that the drug company is doing what it can, to keep those earliest patients on the trial, before the drug is approved for ECD. Any current patient whose needs to be on Cobimetinib and is having difficulty getting access is encouraged to have their doctor contact Dr. Eli Diamond at +1-212-639-7576.
- The wife of an ECD patient came on. He is about to move into a sheltered/supported housing apartment, and is excited about this. When he is excited, or wants to do something, it is hard sometimes for everyone to accommodate him. His physical health is better now than in a long time; and as a result, he is now "Mr. Independence" and this is his chance to prove it. Hopefully it will be easier for everyone to deal with him once the move has happened.
- After the Chat had finished a member came on and gave the sad story of a recent medical problem. Earlier on that day, he had had the urge to pass urine. But the urge "Hit me like a train outta control". He "needed to run" to the restroom, but he can't run anymore. Unfortunately, he only managed to get as far as the bathroom door. He tried to clean up, but couldn't remain standing. After about an hour and a half, he managed to get back to the couch, but he was exhausted. He was "also broken hearted" because he doesn't want "his bride" to see him like that, and "she wound up having to clean me up".

