

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

### **27 May 2017**

6 Attendees

- Some members had been hard at work gardening. One said that hiring a landscaper was "the best decision I ever made". He used the sun sensitivity caused by vemurafenib (V) as his excuse to his wife, but now he is on dabrafenib (D) and has no excuse. Dabrafenib causes very little sun sensitivity. He is taking a dose of three in the morning and three in the evening of the 50mg pills. He thinks that the dose will be reduced, as "There's no reason why I should be on a full dose". He was asked about the costs involved in the V and D treatments. He said that the costs were the same, \$0!!!!
- A member goes to MN in July to see Dr. Go. He has been on D for three months now. He started on V, but had too many side-effects. D is fine, although he has problems with hands and feet, and painful knots. He has a headache in the morning, but that goes away. He is due a scan in two weeks, but not at Mayo. He gets it done locally, in Chicago, and takes the results to Mayo. He has not yet had a scan while on D. He thinks that the D is helping clinically; he feels good, but "the scan will tell all". He still has pain in his humerus, knee, and ankle, "but I live with it". He hopes to reduce D after his next visit. He is taking two pills twice a day = 300 mg per day.
- A member who is now in remission is just taking one V a day. If he switches to D, which he has considered, it will be hard to tell if D is working. He said that he almost needs "to stop V, wait for a relapse, then start D". The risk is, that if D doesn't work for him, and he switches back to V, V may not work anymore. That seems too risky for him!
- A member said that he still has finger pain in addition to leg pain. He sometimes feels like he cannot move his fingers separately. When he is at the masseur, he passes his fingers under the water jets.
- A member came on who was waiting in a car in a rainstorm for her sister! She is going to keep seeing Dr. Diamond, but is changing to U of Kentucky locally, since they are also research oriented. She is considering whether to enroll in some clinical trials there. She has had no chemo since April, and will have a brain MRI June 20 to assess the situation. She had shoulder surgery in late May. She is going to see a rheumatologist to get checked out for auto-immune diseases (and she has been tested for Lyme disease, too). She has a PET scheduled for October in NYC.
- The woman whose husband has ECD came on after the Chat. She had had to mow the grass before the rain came down! Her husband saw the ECD doctor this week and will go back in three weeks time. His QT heart interval is still abnormal, so they are reducing the V by half. He also has a swollen right leg. He has had an ultrasound scan, but no results as of yet. He will have to start new medicine to get rid of the fluid. He has appointments coming up with a urologist, neurologist, and psychiatrist.